

**GUIDELINES FOR GUIDANCE PROGRAMMES FOR XHOSA PARENTS WITH CHILDREN  
WITH CEREBRAL PALSY: AN ORTHOPEDAGOGICAL PERSPECTIVE**

By

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I declare that GUIDELINES FOR GUIDANCE PROGRAMMES FOR XHOSA PARENTS WITH CHILDREN WITH CEREBRAL PALSY: AN ORTHOPEDAGOGICAL PERSPECTIVE is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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(Miss T.M. Sello)

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Date

## **SUMMARY**

This research investigated the need of Xhosa parents with children with cerebral palsy in the Eastern Cape for support through specially designed parent guidance programmes. The research problem that was investigated was: Do Xhosa parents with children with cerebral palsy need guidance programmes, and what guidelines can be given pertaining to such programmes? The aim was to determine whether Xhosa parents needed guidance programmes and if so, to provide guidelines that addressed this need. A literature study was done and thereafter a survey was conducted using a questionnaire with closed items to collect data from 180 Xhosa parents with children with cerebral palsy living in the rural areas of the Eastern Cape's former Transkei. They were sampled by using a non-random (purposive) sampling method. One hundred and two (102) parents (out of the total of 180) answered the questions in the questionnaires and returned them by mail. The same types of questions were used to interview 54 parents. The data was analyzed by a statistical analyst by Microsoft Excel spread sheets. Data was presented in the form of tables and pie charts and the researcher interpreted the outcomes in the light of the literature and her own indigenous knowledge of the Xhosa community.

The implications of findings for all Xhosa parents with children with cerebral palsy are that they lack knowledge of issues such as cerebral palsy, inclusive education and how to deal with their children with cerebral palsy. Relationships within the family and the community are affected because of the children's cerebral palsy. Moreover, Xhosa parent guidance programmes are not available in the Eastern Cape or in other provinces in South Africa. As a result, guidelines are provided which may be used for constructing Xhosa parent guidance programmes.

## **KEY TERMS**

Xhosa parents, Xhosa children with barriers to learning and development, cerebral palsy, inclusive education, attitudes of Xhosa parents, guidance programmes for Xhosa parents.

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# **CHAPTER 1: INTRODUCTION TO THE PROBLEM, PROBLEM FORMULATION AND AIMS**

## **1.1 Introduction**

The intention of the researcher in this chapter is to provide a framework and basis for the research problem. The focus is on Xhosa parents with children with cerebral palsy. The aim is to determine their need for parent guidance programmes and to provide specific guidelines for such programmes. With regard to the Xhosa people in the Eastern Cape, Small Enterprise and Human Development (2006) states: "About 6.5 million people or 14% of South Africa's population live in this province. The province includes the former homelands' indigenous Transkei and Ciskei people".

## **1.2 The Eastern Cape situation**

According to Rhodes University (2006), the characteristics of the Eastern Cape Province are: "Poverty, environmental degradation, economic underdevelopment, widespread institutional collapse, and high rates of rural to urban migration and extreme levels of urban and rural unemployment". Moreover, Rhodes University (ibid) identifies various factors which are likely to cause barriers to learning in the Eastern Cape. Furthermore, a single factor, poverty, is selected to demonstrate how this can cause barriers to learning in children. Miles (2004) states that poverty leads to deprivation of basic human needs. The results may be developmental delays and physical, psychological and intellectual barriers.

Miles (ibid) goes on to state that a child with barriers to learning gives rise to:

- Additional impoverishment because of expensive 'cures' and extra time that is needed to look after the child.
- The birth of such a child can be a precipitating factor in the break up of the family as children are seen as the family's future economic security. Fear of the birth of more children with barriers may cause a man to look for another wife in the hope of having 'healthy' children.
- Due to desertion by the husband, the mother becomes the sole provider for the child with barriers. She is forced to seek employment especially when the child requires full time care (usually grandparents care for the child if the mother is working).

- The woman may be unable to pay school fees if the child is already at school and if she is not employed.
- Moreover, many Xhosa parents are not aware of the existence of parent supporting bodies such as Community Based Rehabilitation (CBR), which issues home-based education programmes that may be the only affordable means a parent can use to teach her child at home if, due to financial constraints, the child cannot attend school. CBR also pays school fees for learners with barriers to learning but it is a short-term measure because donor funding for this endeavour is not guaranteed.

### **1.3 Awareness of the problem**

Factors that drew the attention of the researcher to the plight of Xhosa parents with children with cerebral palsy are:

- The researcher has an extensive experience of working among the Xhosa people in the Eastern Cape.
- The realization that factors stated by Rhodes University (ibid) and Miles (ibid) influence Xhosa parents in the upbringing and education of children with cerebral palsy.
- Observation of daily activities at Ikhwezi Lokusa Special School also alerted the researcher to the problems of Xhosa parents. This school is 'next door' to the dwelling place of the researcher. According to the school's learner roll there were 287 learners in 2005, of these 180 (63%) had cerebral palsy. Some parents were accustomed to bring their children before the opening of the school and fetch them one or two days after the closing of school for the holidays. The researcher's opinion was that parents disliked, rejected or did not accept their children with barriers to learning. This was another incentive for undertaking the research in the former Transkei area.
- The researcher was also aware of the intentions of the Department of Education of replacing the old system of provision with inclusive education. The question arose: Will the parents, who are used to special education, accept this new policy? If so, do they understand inclusive education? This question is addressed by the literature study and empirical research and by providing specific guidelines for designing parent guidance programmes.

## 1.4 Preliminary literature study

One of the methods used in collecting data is a literature study. A literature study is essential in this research because it forms the basis for the empirical research. It also provides an orientation to the topic thereby briefing the researcher on the research problem.

### 1.4.1 Cerebral palsy

A detailed exposition of this concept is given in chapter 2.

#### 1.4.1.1 Signs of cerebral palsy

Here cerebral palsy is briefly discussed. The concept cerebral palsy is defined in 1.6.3. In a child the signs may be, among others: lethargy or lack of alertness, irritability or fussiness, an abnormal and high-pitched cry, trembling of the arms and legs, poor feeding abilities and problems in sucking and swallowing, low muscle tone, abnormal posture, favouring one side of the body, seizures and abnormal reflexes (Cerebral Palsy Diagnosis 2006).

#### 1.4.1.2 Types of cerebral palsy

According to Pellegrino (1997:502) types of cerebral palsy can be grouped as follows:

##### 1. *Regional involvement*

The pyramidal tract has been injured.

The resulting condition is spasticity.

Indications of spasticity include: hemiplegia, diplegia and quadriplegia. Sigelman (2006) adds monoplegia and triplegia.

##### 2. *Global involvement*

The injured area is the extrapyramidal tract.

The resulting conditions are dyskinetic and ataxic forms of cerebral palsy.

The two forms, that is, regional and global, cause conditions such as ataxia, athetosis and dystonia (rigidity). Mixed forms of cerebral palsy also exist.

#### 1.4.1.3 Causes of cerebral palsy

Some of the factors that give rise to cerebral palsy are lack of blood supply to the brain before birth, infections, bleeding in the brain, lack of oxygen, severe jaundice and head injuries (National Center on Birth Defects and Developmental Disabilities (NCBDDD) (2006)). It may be added that unknown factors may also cause cerebral palsy in a child.

#### 1.4.1.4 Associated conditions of cerebral palsy

Cerebral palsy has the ability to generate additional problems in a child. Some examples are intellectual impairments, seizures, speech and hearing problems, visual, learning, feeding and nutrition, behaviour, sleep and sensory impairments (Pratibha 2006).

#### 1.4.1.5 Diagnosis of cerebral palsy

According to Cerebral Palsy Diagnosis (2006), cerebral palsy is diagnosed when the doctors:

- Test motor skills and thoroughly examine the child's medical history. They look for slow development, abnormal muscle tone and unusual posture.
- Use specialized tests such as computer tomography (CT) for an imaging of the brain and magnetic resonance imaging (MIR) that shows a picture of the brain and determines damaged brain parts.
- Study the mother's pregnancy, labour, delivery and care received.

#### 1.4.1.6 Treatment of cerebral palsy complications

According to Sigelman (2006) cerebral palsy cannot be cured. However, most symptoms can be treated and/or managed in such manner that they can improve the child's functional abilities. Professionals who may be consulted are the pediatric physiotherapist, pediatric neurologist, pediatrician, orthopedist, physical therapist, occupational therapist or licensed clinical social worker and a case manager.

Pellegrino (1997:511-516) records some treatments such as the use of:

- Orthotics: Braces and splints for preventing contractures and to maintain range of motion.

- Positioning: Devices such as sidelyers, prone wedges and standers are used for addressing tone and movement problems.
- Medication: Muscle tone may be improved by using medicine, for example, to reduce spasticity and rigidity.
- Nerve blocks, motor point blocks and botulinum toxin may also be used.
- Neurosurgery: It reduces spasticity.
- Orthopedic surgery: It is done to lengthen a tendon, for example, a hamstring or Achilles tendon.
- The CAT scan, EEGs and head sonograms can also be used.

#### 1.4.1.7 Prevention of cerebral palsy

Sigelman (ibid) exposes some of the preventive measures such as:

- Rhesus factor (Rh) testing and immunization.
- Prompt recognition and treatment of bacterial infection of the maternal reproductive and urinary tracts.
- Avoiding unnecessary exposure to X-rays and certain medications during pregnancy.
- Education regarding harmful effects of drugs, cigarettes and alcohol during pregnancy.
- Improved treatment of diabetes.
- Prevention of nutritional deficiencies and curing of anemia.
- Treatment of a newborn baby's jaundice with phototherapy in the hospital nursery.
- Enhanced access to early prenatal care.
- Established protocols for assembling pediatric resuscitation teams in the delivery room whenever a distressed baby is anticipated.

It may be assumed that most Xhosa parents may have little or no knowledge of cerebral palsy and the problems it causes and thus need parent guidance programmes.

#### 1.4.2. Inclusive education

Inclusive education is fully discussed in chapter 3. It may be assumed that most Xhosa parents have little or no knowledge of inclusive education and may be in need of parent guidance programmes that contain information on this type of education.

#### 1.4.2.1 General factors that may prevent full inclusion of learners with cerebral palsy

Learners with barriers to learning such as the ones with cerebral palsy, may be excluded from inclusive schools/ordinary schools due to the following (CRIN Resources 2004):

- Gender: Female children may be regarded as the ones who will not survive. They may be excluded from education, deemed unmanageable or excluded from participation in society.
- Poverty (see 1.2): In areas where communities lack access to basic resources, families with children with barriers to learning are often the poorest and the most marginalized. The parent may try to care for the child but may be influenced by negative beliefs, behaviour, and lack of information, knowledge, skills and resources. As a result the family becomes entrapped in a cycle of poverty and exclusion.

It may be assumed that the factors listed by CRIN Resources (ibid) are applicable to parents of learners with cerebral palsy in the Eastern Cape. Such affected parents may be in need of parent guidance programmes.

#### 1.4.2.2 The right to inclusion and justification for inclusion

The following issues, as listed by Howard *et al* (1997:8-9), CRIN (2004) and Lerner *et al* (1998:97) indicate the right of children to inclusive education:

- Inclusive education is part of a strategy for inclusive development; it cannot occur in isolation. The family, community and other sectors must all be involved from the start.
- Inclusive education concerns changing the education system. In such a system all children are accepted, including those with barriers or those belonging to different ethnic groups, gender or age groups.
- Inclusive education is good for all children. It promotes school improvement, better teaching-learning methods and is child oriented.
- If individual learners are expected to live together as adults in future, inclusive education is the best tool for providing an early opportunity of living in a multicultural society, such as, South African society.
- Inclusive education encourages the belief that all people are valued.

The question is: Why has the implementation of inclusive education in the Eastern Cape taken so long? The answer to this question is provided as follows:

#### 1.4.2.3 Opposition to inclusion

Howard et al (1997:9-10) state barriers to implementation that may also be applicable to the Eastern Cape situation:

- Lack of input by regular educators: Most of the educators may resent major changes that occur in their classrooms.
- Lack of empirical evidence: Some educators may regard inclusive education as a political policy. These educators may be of the opinion that schools should not be regulated by politics, but by sound educational practices.
- Practitioner resistance: Teachers may resist inclusion fiercely because they feel comfortable with what they know.
- Protection: Parents may feel that special schools are necessary to protect their children with barriers to learning from rejection by their 'normal' peers in ordinary schools.
- Effectiveness: Parents may think that special school education is more effective for their learners than inclusive education in ordinary schools.

The question is: What type of inclusive education does the Eastern Cape need during the 21st century? A few criteria are identified by Stubbs (2004):

- Education must be comprehensive and go beyond schooling.
- It must target all members of the community, whatever their age, gender, ability, ethnicity or barrier to learning.
- It must be community-based: The community must understand and accept barriers, people with barriers and people of different appearances, behaviour, beliefs and culture.
- It must include attitudes, behaviours, policies and practices, which celebrate diversity within society.
- It must have accessible environments and transport benefiting not just people with barriers but people with young children and elderly people.
- There must be a teaching force trained to respond to individual needs and which is able to manage diversity in the classroom.
- There must be family support and involvement in education, education system support and acknowledgement of family situations.



- There must be life-long and flexible opportunities for education.

#### 1.4.3 Parent reactions

Parents' reactions are defined in 1.6.5. In order to know parents and understand their attitudes, it is essential to state some of the characteristics of parent of learners with barriers to learning, such as cerebral palsy.

##### 1.4.3.1 Traits of parents of children with barriers to learning

Gascoigne (1995:26-33) describes traits of parents of such learners and how they relate to professionals. It may be assumed that Xhosa parents with children with cerebral palsy have similar characteristics.

##### *1. The articulate, assertive and educated parents*

They appear to be confident, understanding, composed, have no fear about disagreements, may know their rights and may have already gained more knowledge about the child's condition through research after the diagnosis of the child's condition. Professionals prefer to work or assist such parents. However, this outward appearance is often a mask. Inside parents feel guilty, inadequate and helpless. Such parents may need assistance through parent guidance programmes.

##### *2. The angry, knowledgeable parents*

They have already gained some information about the condition of the child. They view professionals with contempt because they think that they (parents) are more knowledgeable. They become angry if their knowledge is questioned or disagreed with. They may show how much they know by quoting sections of different Acts of Parliament or circulars of the Department of Education.

Within themselves they are aggressive and confrontational. They cause professionals to lose self-composure and engage in 'lashing back' at the parents. Such parents need guidance in order to be able to co-operate with professionals.

### *3. The acquiescent or submissive parents*

They agree with anything that professionals suggest. They do not engage in increasing their knowledge through research. They are easy to work with. They answer questions posed but seldom impart information spontaneously.

Inside they lack confidence and wait to be given guidance and direction. They are unwilling to criticize openly, but they may have dissatisfaction building up inside. Such parents also need guidance.

### *4. The 'uncaring' parents*

They do not seem to care about the child falling behind in learning, being unable to do mathematics, or about the child's disruptive behaviour. They seem to regard the child's learning as the responsibility of the educator. They do not implement school devised programmes for the improvement of the child's behaviour at home, develop his or her literary skills or assist him or her with homework. Such attitudes are not conducive to the child's growth, learning and education.

Inside these parents may be afraid of the education system, especially if parents experienced poor education. For them qualifications are of lesser importance than getting a job. They also place the education of the child lower than meeting the needs of the child. Such parents are also in need of guidance.

### *5. The angry, ill-informed parents*

They are similar to the angry, knowledgeable parents. They are, therefore, likely to behave in a confrontational manner. Begging them to be reasonable is not effective; instead it may increase their fury. They may also express their anger in writing and reveal how professionals have harassed them. They may even phone the professionals' secretaries or clerks and use abusive language. Professionals may avoid long contact with them by reverting to being brief, succinct and using formalized and legalized responses.

Inside the parents do care about the child. The only hindrance may be that they are unable to understand the child's needs. They may not be able to accept one symptom of their child's

special barriers such as slow learning. They may not understand the education of such a child. They misinterpret different roles of professionals, for example, if a professional asks a question asked previously by another, their irritation increases. They confuse the roles of professionals such as that of a psychologist and a teacher, a doctor and a therapist.

#### *6. The combative parent*

Parents like to engage in arguments with professionals or education authorities. They are not so interested in their own and the child's needs but in the 'fight'. Like the angry and knowledgeable parents, they quote in detail the Acts, Regulations, Circulars, court proceedings and may readily take their opponent to court.

Within themselves they are interested in the child. They regard professional as 'gatekeepers' and being engaged in the 'battle' with 'gatekeepers' becomes their main interest (hobby). They are very annoyed by administrative mistakes or time delays. They cannot understand why professionals 'cannot see' what is so obvious to them (the parents).

#### *7. The special needs parents*

Some of the parents may have the same barriers as their children. If they have a special problem, such as speech problem, the ability to express themselves may be affected. If what they say is written, as understood by the professionals, and does not reflect what they actually meant (misinterpretation), they become extremely angry.

Inside the parents are interested in the child. The only problem they have are the professionals who 'misinterpret' what they say. Thus, they feel marginalized, and their views and knowledge are belittled (trivialized). Moreover, such parents may need repetition of what they have been told (whatever is said must be explained more than once especially if parents have learning problems).

#### 1.4.3.2 Factors affecting relationships between parents and professionals

Gascoigne (ibid) goes on to state factors affecting the relationship between parents and professionals. These include:

1. *Paid/unpaid:* Parents may resent the fact that professionals receive salaries whether they do their work or not.
2. *Compulsory/voluntary:* Many parents do not 'enjoy' the fact that their child has barriers to learning. Parents feel that they did not volunteer to have such a child; yet to care for such a child is compulsory. They regard professionals as doing voluntary but paid for work. These feelings affect them.
3. *Permanent/part-time job:* Stress and strain of caring for a child is a lifelong experience for parents. For professionals their involvement with the child and his or her parents is temporal and mostly episodic. They can apply for a job elsewhere, be promoted or stop doing that job. There is no option for parents; they must care for the child. This feeling also affects parents.
4. *Continuous/sporadic:* Parents are continuously responsible for their child's needs for twenty-four hours per day, seven days per week. The only exception is when the child is in a boarding school or at a day school. Professionals work for certain hours. They have extra time for other duties or can relax after hours. Professionals, in addition, have holidays. Parents resent this and the fact that they do not have a 'day off' or holidays
5. *Untrained/trained:* Usually parents find out on their own how to deal with their child's barriers to learning. They also have to find out how to solve problems they encounter. In short, they learn as their child grows and develops. They may also acquire knowledge from books or parent support groups. All professionals have been trained for the jobs they do and have special qualifications. Parents, on the other hand, have 'hands on' training, that is, self-taught skills. This state of affairs may also impact negatively on parents and affects parents' co-operation with professionals.
6. *Inexperienced/experienced:* Professionals are trained experts. However, the most experienced ones in the process of identification, assessment, provision and review are parents. This implies that professionals will not know the child with barriers as intimately as parents do.
7. *Whole child/one aspect:* The parent sees the child as a whole. Professionals, unlike parents, see or attend to different aspects of a child. For example, they separate the child's educational, therapy, social and health aspects.

It may be deduced that both parents and professionals need to be made aware of their differences. Awareness may improve relationships between these two parties. In addition to awareness, parents can address these problems during parent guidance meetings.

## **1.5 Parent guidance programmes**

It may be stated that the preliminary literature study on cerebral palsy (see 1.4.1), inclusive education (see 1.4.2) and parental attitudes (see 1.4.3) indicate a need for guidelines for parent guidance programmes.

Gascoigne (1995:34-38) has illustrated some obstacles to co-operation between parents and professionals (see 1.4.3) while Hornby (1995:106-160) supplied the following brief information on how parental guidance should be conducted:

### **1.5.1 "Breaking the ice"**

In order to encourage parents to work together with professionals, in particular educators, in inclusive settings, use can be made of:

- Different types of activities such as school productions (plays), open days/evenings (to see classes in progress or displays), outings (to parks) and gala days (for raising funds).
- Methods of ensuring contacts can be in the form of personal invitations (individually addressed letters/invitations), organizing minibuses (taxis) to pick-up parents, a welcoming atmosphere, opportunities for informal communication, refreshments and inviting parents to evaluate activities.
- Home visits may also be effective. They should be prearranged. Educators to dress informally when visiting, be courteous, have listening skills, ask questions about the children and demonstrate skills to overcome irritations during home visits.

### **1.5.2 Parent-teacher group meetings**

Parents can be informed by using methods stated under 'breaking the ice'. Other strategies may be:

- Encouraging parents to attend by sending notices informing parents about the topic for the next meeting.
- Establishing rapport during the meeting through welcoming parents and thanking them for coming.
- Structuring: Time limits should be set because limits reduce irrelevant discussions. The purpose of the meeting must be stated and agenda items listed. Parents must be asked if

they have any other issues or concerns and these must be added to the agenda.

- Note taking is essential especially if there are important facts or activities that need to be done after the meeting.
- Providing or obtaining information from parents to make them 'open up' and share ideas.
- Use of problem solving techniques may be used to solve disagreements.
- If possible, evaluation of the meeting should be done and the date for the next meeting be set.

### 1.5.3 Group leader

The leader must have skills such as the ability to listen, develop trust within the group, focus on goals of the whole group and of individuals within it, be spontaneous, responsive and firm and have a sense of humour. The group must feel that the leader is with them and for them. He or she must have:

- Reaction skills: Restate, clarify and summarize what is/was said or discussed.
- Interaction skills: Moderate talking, interpret, link, block undesirable actions, support, preserve rights of members, protect members from criticisms or hurts and allow consensus-taking.
- Action skills: making use of questions, probing, tone-setting, confronting to make members face things about themselves, personal sharing and modelling, that is, teaching members interpersonal skills such as listening.
- Know group dynamics: Know the four stages of group development such as inclusion, work, action and termination of a group. Stages are explained as follows:
  - \* Inclusion is the first stage where cohesiveness begins and rules are made.
  - \* Work is the second stage where concerns and issues are resolved.
  - \* Action is the third stage of a group. Members decide what to do in order to address concerns and issues.
  - \* Termination is the final stage where group work is completed.

In the four stages stated above, group members acquire something that can help them. It is suggested that the leader be qualified and experienced if he or she has educators and parents in one group.

#### 1.5.4 Some examples of parent programmes

Hornby (ibid) continues to provide some examples of programmes for parent of learners with barriers to learning. The researcher was unable to locate any new parent guidance programmes for Xhosa parents with children with cerebral palsy in the Eastern Cape.

##### 1.5.4.1 Parent Education Programme (PEP)

This programme facilitates communication and improves relationships between parents and their children. Parents are taught listening skills, expression of their feeling using the 'I' and not 'you' method, how to analyze ownership of a problem and how to use the 'no-loser problem solving' method.

##### 1.5.4.2 Systematic Training for Effective Parenting (STEP)

This programme assists parents to develop a better understanding of their children's behaviours, improve communications with them and increase parents' influences over their children's behaviours.

##### 1.5.4.3 Transactional Analysis (TA)

Although mainly a psychotherapeutic school of thought, it increases parents' understanding of their relationships with their children. It also encourages better communication in the family.

##### 1.5.4.4 Behavioural Group Training (BGT)

This programme is for parents of children with behaviour problems or barriers to learning. Parents are taught behaviour analysis and learn to understand problems of their children.

##### 1.5.4.5 Parent Effective Training\_(PET)

The programme focuses on parents' emotional needs. Parents discuss their concerns and opinions and express their feelings about their children. The programme assists parents to understand and come to terms with their roles as parents. It also improves parent-child relationships.

#### 1.5.4.6 Other programmes

Caregivers such as grandparents, fathers and siblings can also form their own groups. Their programmes may include the use of a workshop format or a meeting format. Advocacy training may also be given in order to give parents and caregivers training in obtaining the best services for their children or to know the rights of children with barriers to learning.

### 1.6 Clarification of concepts

#### 1.6.1 Xhosa parent

The term parent refers to the primary caregiver of the learner (Engelbrecht *et al* (1999:171). The researcher defines Xhosa parents as Nguni parents such as the father and mother or guardians who care for the Xhosa child. Their mother tongue is isiXhosa. Most of these parents, as 1.1 indicated, live in the Eastern Cape.

#### 1.6.2 Xhosa child with barriers to learning and development

Burden (2000:29) defines barriers to learning and development as those factors that lead to the inability of the system to accommodate diversity; lead to the learning breakdown; or prevent learners from accessing education provision. In this manner learners are disabled and others are disadvantaged.

Burden (*ibid*) goes on and lists the factors as:

- Socio-economic barriers such as lack of access to basic services, poverty, underdevelopment, physical psychological factors that put learners at risk.
- Attitudes, language and communication barriers, an inflexible curriculum, inaccessible and unsafe built environments, lack of provision for basic services, lack of enabling and protective legislation and policy, lack of parent and community recognition and involvement, barriers to and lack of human resource development strategies.

In this study a child with cerebral palsy may be regarded as a child with barriers to learning and development. Facts that Burden (*ibid*) stated in 1.6.2 are also applicable to a Xhosa child with cerebral palsy.



### 1.6.3 Cerebral palsy

The term cerebral palsy refers to a "disorder of movement and posture that is due to a non-progressive abnormality of the immature brain. Although the brain continues to grow into early adulthood, the crucial events of its development occur during the intrauterine life and early childhood. Events or conditions that disturb the usual unfolding of this process can result in cerebral palsy. Cerebral palsy, in turn, produces associated barriers such as intellectual impairments, seizures, visual and auditory impairments" (Pellegrino 1997:499).

The researcher in this study regards the concept cerebral as referring to the brain, while palsy means weakness or problems with the use of muscles. Cerebral palsy is, therefore, a group of problems in a person. The disorders affect, among others, the person's ability to develop, move, keep his or her balance and body posture. All these problems result from an injury to the brain prior, during and after birth. Visible signs of cerebral palsy may be clumsiness or an inability to move.

### 1.6.4 Inclusive education

According to Potterton (2003:19) there are numerous and different definitions of inclusive education. Potterton states elements that should be evident in an inclusive school. The school ought to:

- Reflect the community as a whole.
- Be accessible to all who join it.
- Collaborate with other schools and organizations.
- Be democratic and emphasize members' rights and responsibilities.

Potterton (ibid) go on to state that: "Many educators and education officers are worried that schools and other learning sites in South Africa are not equipped to handle full-scale inclusion. It is also obvious that some learners may require more intensive and specialized support".

Howard (1997:6-7) attempts to define inclusive education by referring to or looking at four terms: Mainstream, least restrictive environment, integration and full inclusion.

1. *Mainstreaming*: Learners who have barriers to learning participate in programmes designed for 'normal' children, especially where barriers do not affect their performance as compared to the majority of their peers.
2. *Least Restrictive environment (LBE)*: This is a legal term that is used to define the rights of learners with barriers to learning, to be educated in settings where they are not segregated from learners without barriers to learning.
3. *Integration*: In this type of situation learners with barriers to learning are placed in specialized and separate classrooms within a public school. Special education programmes are used when teaching them. Such learners are excluded from school functions because they might be disruptive.
4. *Full inclusion*: The learners become full time members of a programme they might attend if they did not have barriers. The learners with barriers contribute to the heterogeneous group of learners.

The researcher in this study defines inclusion as a situation where a learner with barriers such as cerebral palsy receives the same type of education, in the same setting, together with 'normal' children. In such a system the learner with barriers to learning such as the one with cerebral palsy has a right to receive any special assistance he or she may need and deserve.

#### 1.6.5 Attitudes of Xhosa parents

An attitude is "the general tendency of an individual to act in a certain way under special conditions. The general tendency can be displayed in two kinds of actions: What the individual does and what the individual says. In other words, an attitude is defined as a favourable or unfavourable reaction towards something or someone and is exhibited in one's beliefs, feelings or intended behaviour" (Shapiro 1999:9).

The researcher defines the phrase: attitudes of Xhosa parents, as a way of believing, feeling and acting towards the Xhosa child with a barrier to learning such as the one with cerebral palsy. The three aspects: Belief, emotion and behaviour/action may either be positive or negative. Positive attitudes may be regarded as pulling the parents towards their child. Negative attitudes may cause parents, for example, to avoid the child.

### 1.6.6 Guidelines for guidance programme

The Illustrated Oxford Dictionary (1998:360) describes a guideline as a principle for directing action. The researcher regards a guideline as a general law that guides or gives direction to the act of constructing a guidance programme for Xhosa parents with children with cerebral palsy.

### 1.6.7 Guidance programme for Xhosa parents

Guidance refers to an advice or information aimed at resolving a problem. It is also an action or process of guiding or being guided (Illustrated Oxford Dictionary 1998:360). In this study guidance for Xhosa parents is described as an advice or information given to a group of Xhosa parents. The parents may require such information because they have a common problem such as not knowing how to raise a child with cerebral palsy.

## 1.7 Statement of the problems

### 1.7.1 Factors leading to the undertaking of research

The preceding discussion exposed the following:

- Factors such as poverty cause barriers to learning in Xhosa children in the Eastern Cape (see 1.2).
- The researcher's awareness of the problem confirmed that certain Xhosa parents have children with cerebral palsy in the Eastern Cape (see 1.3), therefore, research on these parents could be conducted.
- The researcher was also aware that parents react poorly towards their children with cerebral palsy (see 1.3). This could be avoided if they receive parent guidance.
- The fact that parents do not send the children to ordinary schools indicates that they feel comfortable with the type of special education their children receive in special schools. The parents in most cases bring children to such schools while they were still very young and are placed in a special preschool. However, the researcher is aware of the changes required by inclusive education.
- There is little or hardly any participation by parents in the education of their children (see 1.4.2, Potterton 2003:20).

- The researcher has identified a need for guidance programmes for Xhosa parents. Therefore, guidelines ought to be provided for effective programme design. At present school principals lack guidelines and parents have little guidance in the form of workshops, conferences, lectures or discussion groups (see 1.4.1).
- There are also no parent discussion groups pertaining to cerebral palsy in the Eastern Cape. Such groups can educate parents in matters relating to children with cerebral palsy.

#### 1.7.2 The research problem

When taking into consideration factors stated in 1.7.1, the research problem can be formulated as follows:

Do Xhosa parents of learners with cerebral palsy need guidance programmes? If they need guidance programmes, what guidelines can be given pertaining to such programmes?

### 1.8 Research aims

#### 1.8.1 Main aim

The main aim is to determine whether parents need guidance programmes and to provide specific guidelines for constructing guidance programmes where needed.

#### 1.8.2 Specific aims

- To study the literature in order to familiarize the researcher with the topic and to lay the basis for an empirical study.
- To conduct empirical research among Xhosa parents with children with cerebral palsy.
- To provide specific guidelines for parent guidance programmes for Xhosa parents.

### 1.9 Demarcation for empirical research

The study falls within the field of inclusive education. The selected area for conducting research is the Eastern Cape's former Transkei. The target group is Xhosa parents with children with cerebral palsy. Data obtained during research will indicate the need of Xhosa parents of such children for guidance programmes. Based on this need, specific guidelines will be provided.

### **1.10 Research methodology**

The researcher has used a triangulated method for collecting data. The researcher first engaged in:

- Literature study: Research commenced by looking for information in the literature. This is followed by the empirical research.
- The empirical research (see chapter 5 and 6): Data collection was carried out by a questionnaire.

### **1.11 Importance and expected results of this research**

It is envisaged that the research will:

- Reveal new insights/information about Xhosa parents of children with cerebral palsy in the Eastern Cape.
- Make parents aware of their need for guidance programmes and this will lead to requests to professionals to provide them with the material.
- Influence some authors to translate English literature on cerebral palsy and parents of children with cerebral palsy into Xhosa, to assist parents gain a better understanding of the condition.

### **1.12 Limitations of research**

It may be stated that the

- Validity of the research could be affected by the researcher's subjective interpretations. The results may also be of limited predictive value.
- Home visits, which are essential for obtaining additional information, could not be undertaken due to geographical conditions. Parents lived too far away.
- Reliability could be affected by the presence of bias.

### **1.13 Research process**

*Chapter 1:* Serves as an introductory chapter. It contains awareness to the problem, preliminary literature study, clarification of terms, statement of the problem, research aims, research

methodology, importance of research, limitations of research and the programme of study.

*Chapter 2:* Discusses cerebral palsy.

*Chapter 3:* Investigates inclusive education of Xhosa learners with cerebral palsy.

*Chapter 4:* Explores Xhosa parents' attitudes.

*Chapter 5:* Contains discussions on research methodology.

*Chapter 6:* Presents the results of data analysis obtained by using Microsoft's Excel spread sheets. The results are in the form of tabular presentations, pie charts, or any other analysis suitable for the collected data.

*Chapter 7:* Provides specific guidelines for constructing Xhosa parent guidance programmes.

*Chapter 8:* Summarizes the whole research process, states research contributions to existing theories, states limitations of the study and makes recommendations for future research. It will also include a conclusion.

## **CHAPTER 2: AN INVESTIGATION INTO THE PHENOMENON OF CEREBRAL PALSY AND SUPPORT SERVICES**

### **2.1 Introduction**

The aim of Chapter 2 is an exposition of the condition known as cerebral palsy. The definition of the term given in chapter one (see 1.6.3) has already indicated the causes, results and need for support services for those with cerebral palsy. According to Cerebral Palsy Facts, Information and Resources for Parents (2002), cerebral palsy cannot be cured and the child has the condition throughout his or her life. But recent studies suggest that cerebral palsy may be cured in future (EurekAlert 2002).

In this chapter a brief history of cerebral palsy, the incidence, causes, types, associated disabilities, its prevention, different types of support, the brain plasticity and prognosis with regard to cerebral palsy will be discussed.

### **2.2 Brief history of cerebral palsy**

Cerebral palsy is not a new disorder. Although infants have been born with cerebral palsy since time immemorial, the medical sector did not study this condition until 1861. In that year, Dr. William John Little, an English orthopedic surgeon, published the first article containing a description of the neurological problems of children with spastic diplegia. Spastic diplegia manifested itself in the first year of childhood and children displayed stiff spastic leg muscles and to a lesser degree, arm muscles. These children had difficulty in grasping objects, crawling and walking. They did not improve as they grew up nor did they become worse. Spastic diplegia is grouped under an umbrella term: cerebral palsy (National Institute of Neurological Disorders and Strokes 1993-2001).

The term, cerebral palsy, came into use in the late 1800s. It is believed that Sir William Osler, a British medical doctor, coined the term. Dr Sigmund Freud, an Austrian neurologist, who is better known for his work in psychiatry, published some of the earliest medical papers on cerebral palsy. In the early years Little said that most cases of cerebral palsy were caused by obstetrical complications at birth. He was of the opinion that children born with cerebral palsy acquired it because of complicated deliveries and that it resulted from lack of oxygen to the brain of the child. He stated that oxygen shortage damaged sensitive brain tissues controlling movement. In

the late 1800s Freud disagreed with Little's opinion. Freud recorded that children with cerebral palsy often had other problems such as intellectual impairment, visual disturbances and epileptic seizures.

Freud suggested that cerebral palsy might be acquired earlier in life, that is, during the development of the brain in the womb (Cerebral Palsy Facts, Information and Resources for Parents 2002). With regard to difficult births Freud wrote that in certain cases it was a symptom of "deeper effect that influences the development of the foetus" (Cerebral Palsy Facts, Information and Resources for Parents 2002).

In spite of Freud's opinion, physicians, medical researchers and parents continued to believe that birth complications caused cases of cerebral palsy. It is only as recently as 1980s that scientists began to undertake an extensive analysis of data from the United States Government Study of more than 35 000 births. While they found that birth trauma was the cause of thousands of cerebral palsy cases, no such cause could be found in the majority of the cases. They realized that birth trauma formed a fraction of the causes of cerebral palsy, that is, less than 10 percent. This state of affairs influenced researchers to explore other causes and look at medical theories about cerebral palsy more closely (National Institute of Neurological Disorders and Strokes 1993-2001).

Cerebral Palsy Facts, Information and Resources for Parents (2002) is convinced that even nowadays, professionals still have erroneous ideas about the physical and neural skills of children with cerebral palsy. Separating children from their families at an early age and placing them in residential institutions indicates this. Cerebral Palsy Facts, Information and Resources for Parents (2002) states: "Fortunately in the past few decades, information on the many facets of cerebral palsy significantly increased. Today the medical community has great interest in studying cerebral palsy to determine its causes and the most effective ways to treat it. As knowledge and treatment techniques have expanded and improved, so too have the prospects of all children with cerebral palsy."

### **2.3 The incidence of cerebral palsy in some countries**

The history of cerebral palsy (see 2.2) has showed that this condition has been known as a phenomenon for a long time. Authors confirm its existence by providing figures, thus establishing its incidence. Special attention will now be given to statistics in selected countries.



### 2.3.1 United States of America

The National Information Center for Children and Youth with Disabilities (NCHCY 2002:2) reports that 3/1000 live births are born with cerebral palsy each year and that another 500 acquire it in the early years of life. Opelousas Area Cerebral Palsy Clinic (2001) records that 2½/1000 live births (5 out of 2000) are born with cerebral palsy. This incidence has remained constant for the last 30 years, despite the developments in obstetrical and paediatric care. The National Information Center for Children and Youth with Disabilities (NCHCY 2002:2) goes on to explain that "...the uniformity is misleading, however, because although improvements in medical care have decreased the incidence of CP [Cerebral Palsy] among some children who otherwise would have developed the disorder, medical advances have also resulted in the survival of children who previously would have died at a young age and many of these children have an impairment of a disability such as cerebral palsy".

### 2.3.2 The United Kingdom

In the United Kingdom the incidence of cerebral palsy has been reduced by improvements in maternity and neonatal care. This implies that fewer babies develop cerebral palsy as a result of lack of oxygen (from difficult birth) or jaundice. This also means that more babies with very low birth weights survive. The babies are more likely to have cerebral palsy (Cerebral Palsy Helpline 2001).

Cerebral Palsy Helpline (2001) further states that there has been a slight increase, in recent years, in the number of children with cerebral palsy. At present about 1/400 live births are affected. Among these the percentage of the severely and multiple disabled people is increasing.

### 2.3.3 Sweden

The Swedish's Cerebral Palsy and Conductive Education (2001) pamphlet states that the country has 4 000 children with cerebral palsy (4/1000) live births. It indicates no reason for this high incidence. Therefore, the Swedish incidence of cerebral palsy is higher than that of the United States of America and the United Kingdom.

#### 2.3.4 South Africa

In South Africa the White Paper on Integrated National Disability Strategy (1997:1) states: “There is serious lack of reliable information on the nature and prevalence of disability in South Africa. This is because, in the past, disability issues were viewed chiefly within a health and welfare framework. This led naturally to a failure to integrate disability into mainstream government statistical processes.

Statistics are unreliable because of the following reasons:

- There are different definitions of disability,
- Different survey technologies are used to collect information,
- There are negative traditional attitudes towards people with disabilities,
- There is poor service infrastructure for people with disabilities,
- Violence levels (in particular areas at particular times have impeded the collection of data, affecting the overall picture.”

Evidence of lack of exact statistics for children with disabilities is supported by Carlsisle in the Saturday Daily Dispatch of May 11 (2002:7). It states, “There are few statistics available on the prevalence of childhood disability, but it could be as high as five percent of South African children”. Statistics for children with cerebral palsy in South Africa seem to be lacking also. Tredoux (2000:27) states: “According to a survey for the Department of Health, South Africa, 1999, there was no clear category for children with cerebral palsy. But from a sample size of 2223 people the following causes of cerebral palsy were portrayed; illness, 26%, don’t know, 21%, before or during birth, 19%, accident, 15%, other, 9%, violence, 5%, witchcraft, 3% and ageing process, 2%.”

#### 2.3.5 Eastern Cape

It is difficult to obtain the exact incidence of cerebral palsy in the Eastern Cape. The number of children with this condition is lacking. Reasons for a lack of firm numbers are possibly similar to those stated in 2.3.4.

Thus, it may be assumed that the lack of statistics is the result of these reasons:

- Some children with disabilities are in ordinary schools (nowadays mainstream schools must include all learners).

- There are no studies on children with disabilities who leave school early.
- Some children may be kept at home by parents owing to factors such as poverty, ignorance and traditional practices.
- The high infant mortality rate hampers attempts to obtain stable incidence figures of children with cerebral palsy.

While Eastern Cape figures are lacking, it may be argued that they are probably similar to statistics gathered in the United States of America, United Kingdom, Sweden and in other provinces of South Africa. They may range between 1/000 and 5/1000 live births.

To obtain a clearer picture of cerebral palsy, factors causing cerebral palsy in a child and the extent or consequences of the damage are discussed.

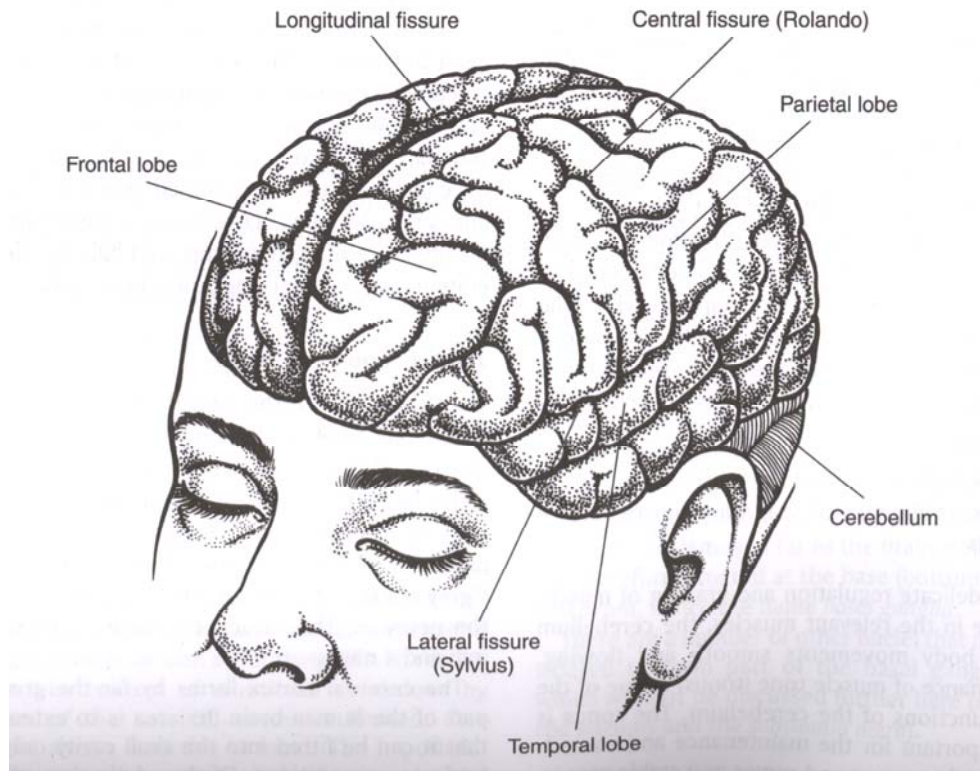
## **2.4 Neurological basis of cerebral palsy**

Lynch and Batshaw (1997:293) are of the opinion: “The nervous system is the body’ compute, yet it is far more complex than the most advanced compute ever built. It co-ordinates and directs various body systems via billions of cells, which connect in the central nervous system (CNS), consisting of the brain and spinal cord, and the peripheral nervous system. The peripheral nervous system is further divided into somatic nerves system, which includes sensory and motor nerves, and the autonomic nervous system, which controls automatic functions such as the beating of the heart. Each component of the nervous system controls some aspects of behaviour and affects our interaction with the world around us. An impairment of any part of this system makes us less able to adapt to the environment and can lead to disorders as diverse as mental retardation, learning disabilities, cerebral palsy, meningomyelocele, and epilepsy”.

The structure and functions of this system are, therefore, discussed because disorders in the system may cause cerebral palsy.

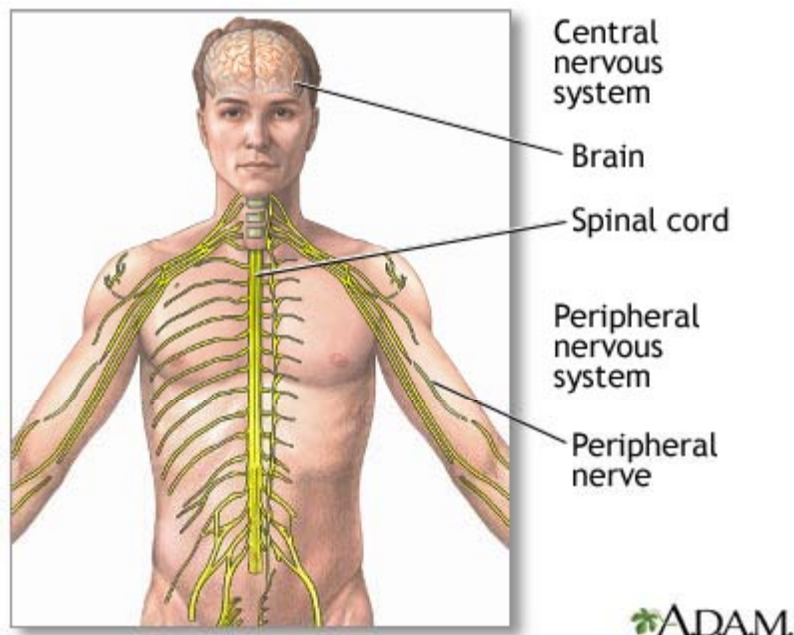
### **2.4.1 The brain**

The brain is the great nerve centre of the body. It is part of the central nervous system and is located in the skull. Figure 2.1 indicates the position of the brain in the skull. The lobes and fissures are clearly visible.



**Figure 2.1** The human brain

Source: Kapp (1994:217)



**Figure 2.2** The central and peripheral nervous system

Source: <http://www.nlm.nih.gov/medlineplus/ency/article/000716.htm>

The brain consists of grey matter and white matter. The cortex and nerve centres are grey and the areas in between are white. The grey colour is produced by numerous thousands of cell bodies and the white indicates the colour of the myelin. This white area shows the bundles of axons (nerve fiber projections) passing through the brain (Cardoso 2002).

According to Gale Encyclopedia of Childhood and Adolescence (1988) the human brain is a soft, shiny, grayish white mushroom-shaped structure. The brain of an average adult weights about 390g (13.7 oz). The brain is protected by the skull and is covered by three membranes or meninges:

- The dura mater, which is a dense, fibrous tissue, contains many blood cells. It is smooth towards the inside but is a tough sheath attached to the bones of the skull.
- The arachnoid mater is just beneath the dura mater. It is a delicate and transparent membrane.
- The pia mater is the innermost layer. It consists of connective tissue and has numerous blood vessels. The functions of this layer are (Gale Encyclopedia of Childhood and Adolescence 1999):
  - \* To allow glucose, oxygen and certain ions to pass from the blood vessels into the brain;
  - \* To prevent substances such as antibiotics from passing through to the brain;
  - \* Blood vessels in this layer transport waste products produced by the brain's activities.

Cerebrospinal fluid is found in the space between the arachnoid membrane and pia mater. This fluid:

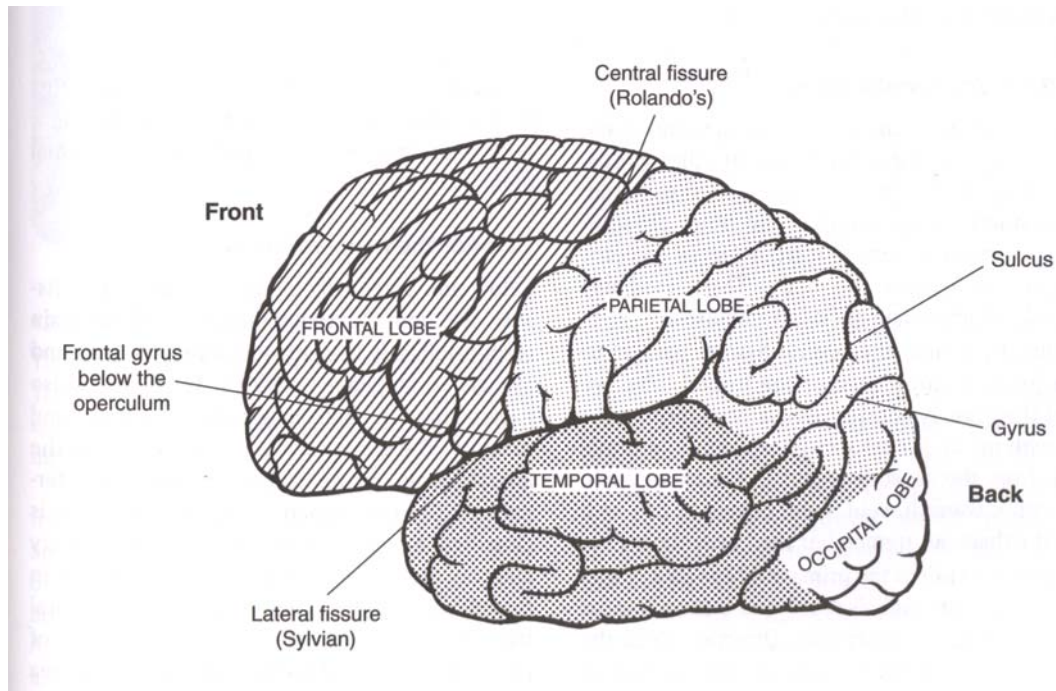
- Prevents friction, jarring and shock;
- Carries away the brain's waste products.

If the fluid is produced in excess, the result is the condition called hydrocephalus or 'water on the brain'.

The permeable pia mater allows glucose, oxygen and certain ions to pass from the blood into the brain but other substances such as antibiotics cannot pass through (Gale Encyclopedia of Childhood and Adolescence 1999). Cerebrospinal fluid forms the waterbed for the spinal cord. Sometimes the membranes surrounding the brain may become inflamed. An acute inflammation

produces cerebrospinal fever while a chronic inflammation is due to tuberculosis or syphilis (Hannover Re 2001).

The brain consists of lobes such as the frontal, which is associated with movement, the parietal which is responsible for all somatosensory or somesthetic functions, the occipital which analyses and interprets visual stimuli, and the temporal which controls auditory abilities and associated language activities.

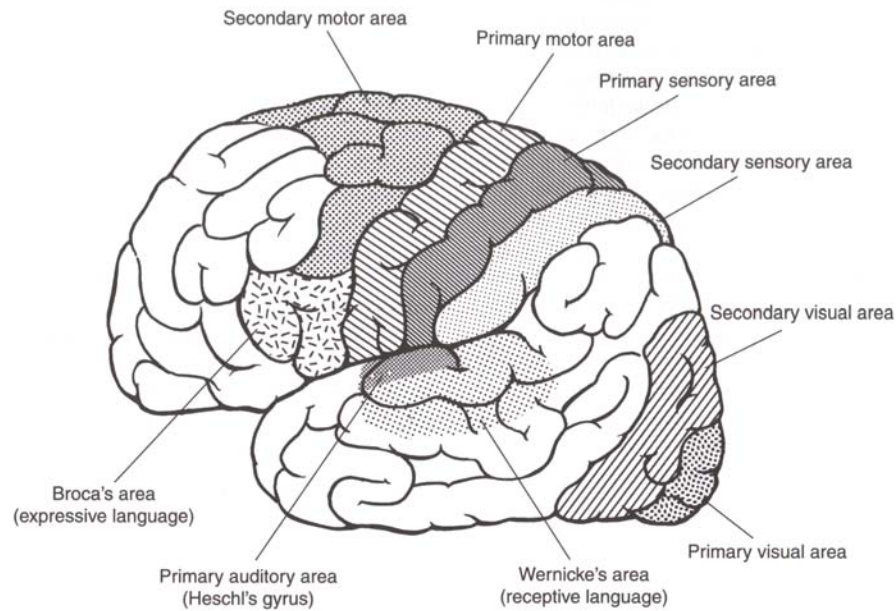


**Figure 2.3** Lateral view of left cortical hemisphere of the cerebrum

Source: Kapp (1994:218)

#### 2.4.1.1 The cerebrum

The cerebrum is the main part of the brain. It constitutes about 90% of the weight of the brain. The surface covering of the grey matter which forms the outermost layer of the cerebrum is called the cerebral cortex. The word cortex originates from the Latin word 'bark' (of a tree). The reason is that the cortex is a sheet of tissue which comprises the outer layer of the brain. The thickness of the cortex is about two to six millimeters. The cerebral cortex's two hemispheres, the right and the left ones, are connected by a band of fiber nerves called the corpus callosum. In appearance the cerebral cortex has many bulges or gyri and grooves or sulci (Neuroscience for Kids 2002).



**Figure 2.4** Motor and sensory areas of the brain

Source: Kapp (1994:218)

Neuroscience for Kids (ibid) reveals the following functions of the cerebrum and tabulated in table 2.1.

CORTICAL AREA	FUNCTION
Prefrontal cortex	Problem solving, emotions, complex thought
Motor association cortex	Co-ordination of complex movement
Primary motor cortex	Initiation of voluntary movement
Primary somato-sensory cortex	Receives tactile information from the body
Sensory association area	Processing of multi-sensory information
Visual association area	Complex processing of visual information
Visual cortex	Detection of simple visual stimuli
Wernick's area	Language comprehension
Auditory association area	Complex processing of auditory information
Auditory cortex	Detection of sound quality (loudness, tone)
Speech center (Broca's area)	Speech production and articulation

**Table 2.1** Functions of the brain

The cerebrum's two hemispheres differ in the functions they perform. Nel (2001) identifies the functions as follows:

LEFT BRAIN DOMINANCE	RIGHT BRAIN DOMINANCE
<ul style="list-style-type: none"> <li>* Logical/analytical brain hemisphere.</li> <li>* Focuses on detail.</li> <li>* Center for learning new language.</li> <li>* Mathematics-algebra and Trigonometry.</li> <li>* Works from detail to the holistic picture.</li> <li>* Auditory/verbal.</li> <li>* Prefers talking/writing.</li> <li>* Perceives differences.</li> <li>* Objective.</li> <li>* Rational.</li> <li>* Focuses on rules and regulations.</li> <li>* Future oriented.</li> <li>* Needs to plan</li> <li>* Critical/judgment</li> <li>* Focuses on technique.</li> <li>* Can sit still and learn.</li> <li>* Time conscious.</li> <li>* Remembers names, numbers and formulae.</li> </ul>	<ul style="list-style-type: none"> <li>* Creative/Gestalt brain hemisphere.</li> <li>* Focuses on holistic picture.</li> <li>* Center for descriptive language.</li> <li>* Mathematics-geometry and story sums.</li> <li>* Works from the holistic picture to detail.</li> <li>* Visual/spatial.</li> <li>* Prefers drawing/gestures.</li> <li>* Perceives similarities.</li> <li>* Intuition.</li> <li>* Takes own rules and regulations.</li> <li>* Now-oriented.</li> <li>* Takes own initiative.</li> <li>* Impulsive.</li> <li>* Receive information passively.</li> <li>* Innovative.</li> <li>* Needs movement.</li> <li>* Not time conscious.</li> <li>* Remembers colours, faces and shapes.</li> </ul>

**Table 2.2** Dominances of the left and right brain hemispheres

There are four lobes of the cerebrum. A lobe is a well-defined part of an organ. The functions of the four lobes as well as the result of damage to these lobes need also to be discussed.



## 1. *The frontal lobe*

### a) Functions (Traumatic Brain Injury Resources Guide (2001))

- To provide consciousness, that is, how we know what we are doing within our environment.
- To initiate activity in response to our environment.
- To make judgments about what occurs in our daily activities.
- To control emotional responses.
- To control expressive language.
- To assign meaning to the words we choose.
- To make word associations,
- To combine memory for habits and motor activities.

The frontal lobe is thus involved in initiating voluntary muscle movements and in cognition. It has a motor strip just in front of the parietal lobe and it is in this strip that voluntary motor activities are controlled. Along the strip various areas of the body are represented topographically.

The tongue and larynx (voice box) are controlled at the lowest point of the strip. They are followed in an upward by the face, hand, arm, trunk, thigh and foot. The areas of the tongue, larynx and face are larger because motor activities linked with speech and fine motor actions are very complex and need elaborate control (Lynch & Batshaw 1997:303). Voluntary movement starts when nerve impulse in the strip is stimulated. The impulse passes down the pyramidal (see 2.4.1.6) of the corticospinal tract into the peripheral nerve, which leads to a certain muscle. The result is voluntary movement of that specific muscle.

### b) Damage to the motor cortex or pyramidal tract

Damage to the whole cortex results in spasticity (see 2.5.1.1). The involuntary or reflex muscle contractions which are controlled by the brain stem (see 2.4.1.4) and spinal cord (see 2.1) are no longer counterbalanced by voluntary pyramidal activity. Voluntary movements become difficult and muscle tone increases as the case is in spastic cerebral palsy (Lynch & Batshaw 1997:303).

Other signs of damage include (Supratentorial System 2001):

- The reappearance of primitive reflexes, such as grasp and snout. Another common feature is an abnormal increase in resistance to movement and this is called paratonia or gegenhalten.
- Perseveration of motor programmes. It prevents proper behaviour responses to environmental demands. Changing of behaviour from one form to another is very difficult.
- Planning impairments also results. A frontal lobe disease, for instance, causes the person to impulsively initiate unplanned attempts at solving problems. The condition is worsened by the inability to pay sustained attention to a task. The result is distractibility and inability to withhold an immediate but inappropriate response.
- Disturbances of social and emotional behaviour. There are many behaviour disorders but there are mainly two poles of the spectrum:
  - Decreased spontaneity with apathy and blunted affect. This means that there is a reduction in all psychomotor activity with the slowing of mental processes and even drowsiness.
  - This is called abulia (loss or deficiency of will power, the initiative or drive).
  - Outbursts of irrational behaviour with irritability or childish behaviour and carefree joking, silliness and lack of inhibition.

Lehr (2001) confirms that injury to the frontal lobes results in:

- Loss of simple movements of various body parts. This is called paralysis.
- Inability to plan a sequence of complex movements needed to complete multi-stepped tasks, such as making coffee. This is called sequence problem.
- Loss of spontaneity in interacting with others.
- Loss of flexibility in thinking.
- Perseveration, which is the persistence of a single thought.
- Attention deficit, which refers to the inability to focus on a task.
- Mood changes or emotional labile.
- Changes in social behaviour.
- Changes in personality.
- Difficulty with problem solving.
- The inability to express language. This is called Broca's aphasia.

## 2. *The parietal lobe*

Figure 2.3 indicates that the parietal lobe is located near the middle and top of the head. It is, in other words, between the frontal, occipital and above the temporal lobe.

### a) Functions

- It is the location for visual attention.
- It integrates stimuli to form a total impression or gestalt from inputs obtained from different senses.

### b) Damage to the parietal lobe

Other problems may include, as recorded by Lehr (2001) and Lynch and Batshaw (1997:304):

- The inability to attend to more than one object at a time.
- Inability to name an object (called anomia).
- Inability to locate the words for writing (agraphia).
- Problems with reading, this is termed alexia.
- Problems with drawing objects.
- Difficulty in distinguishing left from the right.
- Difficulty in calculating mathematics.
- Lack of awareness of certain parts of the body and/or surrounding space. This is called apraxia and leads to difficulties in self-care.
- Inability to focus visual attention, this is called ocular apraxia.
- Difficulties with eye and hand co-ordination.

## 3. *The temporal lobe*

This lobe is situated near the temple of the skull, hence the name tempora, opposite the outer ear. Figure 2.3 shows that the lobe is at the side of the head, above the ear. The functions of the temporal lobe are to serve as storage and for the retrieval of memory. A person's vocabulary is in this area and specific memories are stored in special areas, for example, proper names are in the anterior temporal tip (Supratentorial System 2001).

Lehr (2001) states the functions of the temporal lobe and the results of its injury as follows:

a) Functions

- Hearing ability.
- Memory acquisition.
- Some visual perceptions.
- Categorization of objects.

b) Damage to the temporal lobe

Observed problems when the temporal lobe is injured include:

- Prosopagnosia, which is the difficulty in recognizing faces.
- Wernicke's aphasia, which refers to the difficulty in understanding spoken words.
- Disturbance with selective attention to what one sees and hears.
- Difficulty with identification of, and verbalization about objects.
- Short-term memory loss.
- Interference with long-term memory.
- Increased or decreased interest in sexual behaviour.
- Categorization problems which refers to the inability to categorize/classify objects.
- Right lobe damage can cause persistent talking.
- Increased aggressive behaviour.

According to Molavi (1997), there are three structures on the surface of the temporal lobe: the olfactory cortex, the amygdala and the hippocampus. These three forms are known as the limbic system (see 2.4.1.5). The olfactory system begins in the roof of the nasal cavity and therein the olfactory receptors detect different smells. The amygdala is housing fear, which is the drive instinct for ensuring survival. It recognizes elements of a scene that indicates danger and provokes instant response. The amygdala is also responsible for the mood and conscious emotional response to an event, be it positive or negative. Damage to the amygdala causes lack of fear. The hippocampus is responsible for memory.

Damage to the hippocampus causes loss of declarative memory. This implies that a person can form no new memories after the injury but he or she can remember events before the injury. Diseases such as seizures, Alzheimer's disease and ischaemia may also cause memory deficit. Supratentorial System (2201) records lesions to the temporal lobe which results in:

- Anterograde amnesia which is the inability to learn new material.
- Retrograde amnesia, which is the inability to remember events that happened before the memory disturbance. The person's oldest memories are the hardest to lose. The amnesic syndrome includes both anterograde and retrograde amnesia; the most prominent is former. The person may also make false memories with regard to recent events. This is called confabulation and it is associated with denial of memory loss.

#### 4. *The occipital lobe*

The occipital lobe is situated at the back of the head, as reflected by figure 2.2. Its main task is vision.

##### a) Functions

Padula and Argyris (2002) report that the visual stimuli are deciphered and 'analyzed' in a place called the visual-receptive area. The image is then processed further in another part of the occipital lobe. From there the image is passed on to the temporal lobes (see 2.4.1.1) and parietal lobe (see 2.4.1.1) lobes. These two lobes determine the location in space and the identity of the object. The image is related to what was heard, or felt in these two lobes, in this manner intelligent interpretation can be made.

##### b) Damage to the occipital lobe

Severe damage to this area leads to "cortical blindness", this means that the eyes see but the occipital lobe does not receive the image. The person is referred to as being functionally blind (Lynch & Batshaw 1997:304; Lehr 2001). Other problems include:

- Visual fields cuts, these are defects in vision.
- Difficulty with locating objects in the environment.
- Colour agnosia which is the difficulty with identifying colours.
- Production of hallucinations.
- Visual illusions, that is, the inaccuracy in seeing objects.

- Word blindness that indicates the inability to recognize words.
- Difficulty in recognizing drawn objects.
- Difficulty with reading and writing.

It can be deduced from the above the discussion that damage to the cerebrum and its lobes may result in cerebral palsy and/or its associated disabilities. Another part that needs to be studied is the basal ganglia.

#### 2.4.1.2 The basal ganglia and thalamus

##### a) Functions

The basal ganglia are below the cerebrum and are alongside and below the thalamus. They stretch as far as the brain stem. Near the basal ganglia is the thalamus. The basal ganglia are part of a large number of nuclei that modify movement. Motor cortex sends the information to them via the thalamus and the basal ganglia send information back to the motor cortex through the thalamus.

##### b) Damage to the basal ganglia

Molavi (2001) records some of the results of injury to the basal ganglia. Lynch and Batshaw (1997:305) are of the opinion that damage to the basal ganglia results in movement disorders. Voluntary movement is possible but it may be exaggerated in a twisting, squirming pattern called choreoathetosis. "Lead pipe" rigidity may be present due to changes in tone. This is an indication of dyskinetic cerebral palsy. Injury to the thalamus may cause petit mal seizures or absence epilepsy (see 2.7.2).

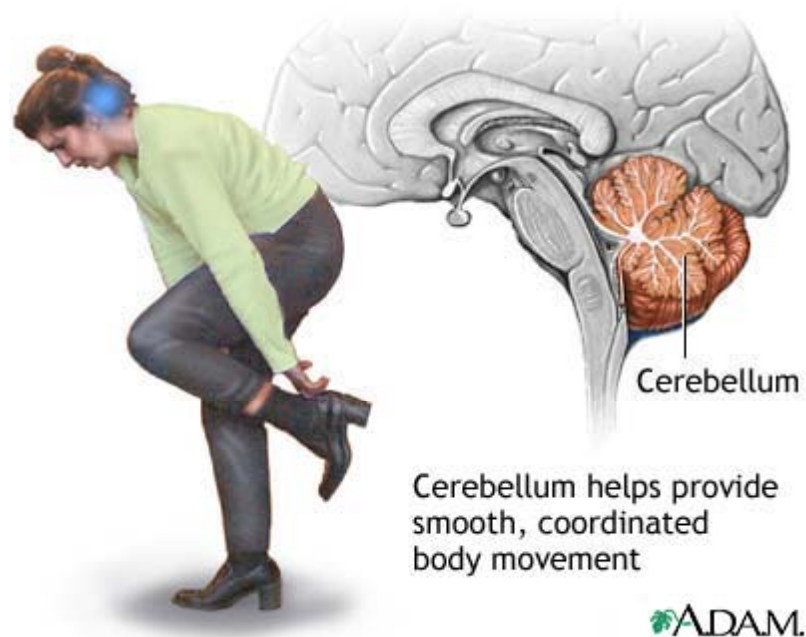
Another part of the brain that needs to be examined is the cerebellum.

#### 2.4.1.3 The cerebellum

This section of the brain develops from the brain stem and is below the cerebral hemispheres and behind the pons. Like the cerebrum it consists of the outer cortex, inner white matter and deep nuclei. It consists of two halves with grey matter on the outside and white matter on the inside. Like the cerebrum it is drawn up into folds but in this case the folds run in parallel lines.

a) Functions

The cerebellum receives fibers from various parts of the body such as from the cerebral cortex via the pons nuclei, receptors in the skin, tendons, muscles, joints, equilibrium organs in the internal ear (the vestibular organs), as well as from the visual and auditory organs. Gale Encyclopedia of Childhood and Adolescence (2001) adds that the received information enables the cerebellum to control actions of the voluntary muscles and times their contractions so that movements can be smooth and accurate. The cerebellum also integrates the work of the cerebral hemispheres and those of the basal ganglia and thus controls the balance of the body.



**Figure 2.5** Location and function of the cerebellum

Source: <http://medicalimages.allrefer.com/large/cerebellum-function.jpg>

b) Damage to the cerebellum

- According to the Gale Encyclopedia of Childhood and Adolescence (2001) and Lehr (2001) injury to the cerebellum causes:
- Ataxia, which is a sign of problems with co-ordination.
- Dysarthria where speech is unclear due to problems encountered when controlling speech muscles.

- Nystagmus, which involves uncontrollable jerking of the eye balls.
- Loss of ability to co-ordinate fine movements.
- Loss of ability to walk.
- Inability to reach out and grab objects.
- Tremors.
- Dizziness or vertigo, this is caused by an inappropriate sensation of body movement which in turn results from the disturbances of the sensory mechanisms for equilibrium.
- Slurred speech or scanning speech. This is an ataxic speech. It is a halting speaking pattern in which every syllable is stressed equally and there is a pause after each syllable. There is no intonation and stress.
- The inability to make quick movements.

#### 2.4.1.4 The brain stem

Like other brain parts stated above, the brain stem also plays a major role in movement and other brain activities.

##### a) Functions:

- The brain stem links the cerebral hemispheres to the spinal cord (see 2.1).
- The three parts of the brain stem, the medulla, pons and midbrain send out 12 cranial nerves which control certain functions such as breathing, swallowing, seeing, hearing and salivation.
- It accommodates parts of corticospinal tract and other nerve tracts that flow from the cortex to the spinal cord and vice versa (Neuroscience for Kids 2002; Washington University School of Medicine 2001).
- It controls heart rate, automatic nervous system for sweating, blood pressure, digestion and temperature, the level of alertness, ability to sleep and sense of balance (Traumatic Brain Injury 2001).

##### b) Damage to the brain stem

Lynch and Batshaw (1997:305) are of the opinion that “children with cerebral palsy often have damage to the brain stem or to pathways that end in the brain stem. This explains why these



children have, in addition to gross motor problems a high incidence of sucking and swallowing problems, strabismus, excessive salivation and speech disorders”.

Other difficulties are decreased vital capacity in breathing which is necessary for speech, inability to organize or perceive the environment, balance and movement problems, dizziness and nausea/vertigo, sleeping disorders such as insomnia and sleep apnea which is the temporal cessation of breathing during deep sleep (Lehr 2001).

The limbic system is another brain part which also has essential duties. When injured, the system causes cerebral palsy in a child.

#### 2.4.1.5 The limbic system

This system lies deeply hidden in the interior of the brain. It consists of the olfactory, gyrus cingulus, subcallosal gyrus, uncus and gyrus parahippocampalis (Molavi 2001).

Molavi (ibid) goes on to state some of the functions of the limbic lobe.

##### a) Functions

- It deals with psychological functions such as the controlling of excessive activity, for example, hyperactivity or restlessness, aggression and the entire emotional life of a human being.
- It assists in human memory.

##### b) Damage to the limbic system

Injury to the limbic system may result in hyperactivity, aggression and affected memory in a child with cerebral palsy.

#### 2.4.1.6 Pyramidal tract

In order to be able to control muscular movements and also glandular secretions, the brain sends messages through basic motor paths. One of the pathways is called the pyramidal tract

or corticospinal pathway. According to Molavi (2001), this pathway originates in the brain or brain stem.

a) Functions

Pyramidal tracts are like the motor of the car. In the body they control posture, reflexes, muscle tone and conscious voluntary movements. They control trunk muscles and enable the hemiplegics to hold their torso upright. The forehead also receives bilateral innervations, that is, stimulus energy (Molavi *ibid*).

b) Damage to the pyramidal tracts

It is evident that when the motor of the car is unable to function, the car will not move. Likewise, in the body the control of the above stated functions are likely to be hampered when the pyramidal tracts are injured. Molavi (*ibid*) adds that if there is a facial paralysis, it is due to cerebral strike or peripheral injury.

#### 2.4.1.7 Extra-pyramidal tracts

Most of the brain parts, such as the basal ganglia (see 2.4.1.2), cerebellum (see 2.4.1.3), parts of the reticular formation and their connections with the motor neurons of the spinal cord and nuclei of the cranial nerves form what is called the extra-pyramidal tracts. In other words, extra-pyramidal tract means neurons function outside the pyramidal tracts. Extra-pyramidal tracts act like the control mechanisms on the car. In the body they control and co-ordinate posture, movements, tone and other activities. Damage to the tracts is likely to throw the body movements 'out of gear', that is, they will be uncontrolled, jerky and uncoordinated.

Cerebral palsy has its own specific classification as the discussion in 2.5 explains.

## 2.5 Classification of cerebral palsy

Cerebral palsy is a wide term encompassing different disorders of movement and posture. In order to be able to describe certain types of movement disorders, pediatricians, neurologists and therapists use several classification systems and labels. Professionals often use the term

muscle tone when referring to different types of cerebral palsy. Cerebral Palsy Facts (2002), for example, explains muscle tone as:

“The amount of tension or resistance to movement in a muscle. Muscle tone is what enables us to keep our bodies in a certain position or posture. Changes in muscle tone are what enable us to move. For example, to bend your arm to brush your teeth, you must shorten or increase the tone of the biceps muscles on the front of your arm, at the same time you are lengthening (reducing the tone of) the triceps muscles on the back of your arm. To complete a movement smoothly, the tone in all muscle groups involved must be balanced. The brain must send messages to each muscle groups to actively change its resistance.”

With regard to children with cerebral palsy, Cerebral Palsy Facts, Information and Resources for Parents (2002) goes on to say that such children have damage to the area of the brain which controls muscle tone. As a result they have:

- a) *Increased muscle tone*: This condition is sometimes referred to as high tone, hypertonia or spasticity. The muscles are stiff and awkward because muscles are too tight and their tone is not balanced.
- b) *Reduced muscle tone*: This disorder is called low tone, hypotonia or floppiness. The muscles are too relaxed and the child needs support to maintain the position.
- c) *Combination of these two tones*: The terms fluctuating or variable muscle tone is used. In such a case both high and low tones are present. When resting the muscle tone is high.

In this chapter not all types of cerebral palsy will be studied but only those that seem to be the most noticeable in children.

#### 2.5.1 Classification of cerebral palsy according to the location of brain injury

When using the classification based on the location of brain injury, professionals deal with three main types of cerebral palsy: the pyramidal or spastic, extra-pyramidal or choreo-athetosis and mixed types.

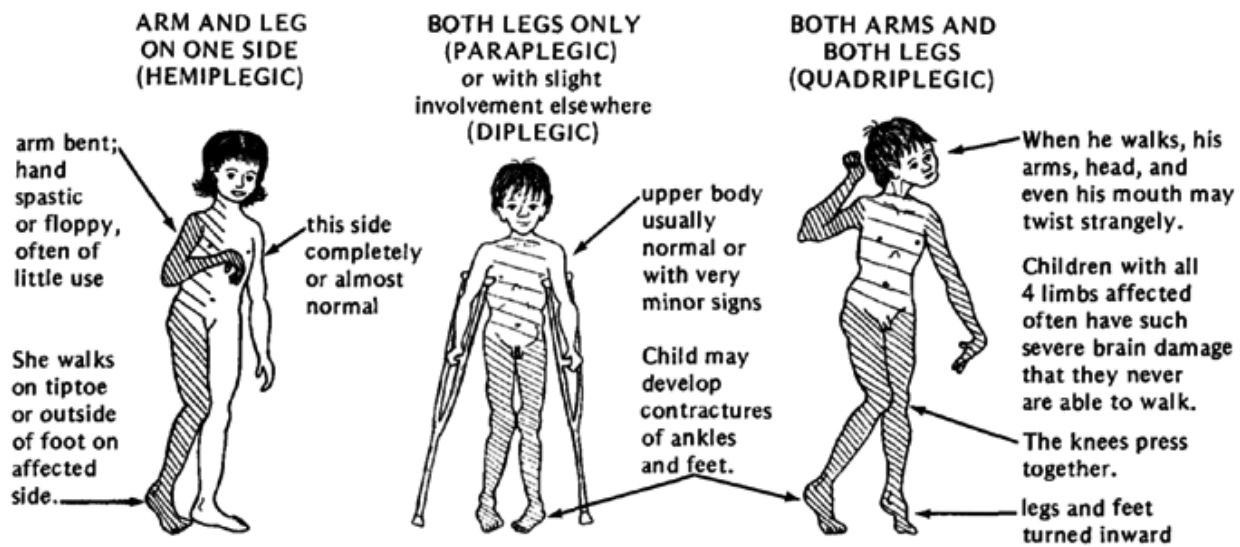
### 2.5.1.1 Pyramidal or spastic cerebral palsy

The term spasticity refers to a disability in a person that is caused by spasms. Spasm is any sudden, convulsive muscular movement. Spasms may be clonic, which means that there is alternating contraction and relaxation of the muscles. The spasms may also be tonic. This implies that there is continuous contraction of a muscle. Spasticity in a child indicates that the brain areas that control movement have been injured, for example, the motor, pre-motor, pyramidal and extra-pyramidal tracts. The National Institute of Neurological Disorders and Strokes (2001) is of the opinion that spasticity may result if some of the spinal cord's nerves are injured. The degree of spasticity ranges from mild muscle stiffness to severe, painful and uncontrollable muscle spasms that often interfere with daily activities of the child with cerebral palsy.

The traits of spasticity in a child include one or more tight muscle groups which limit movement. Such muscles cause children to have a difficult time moving from one position to the other. They also have a hard time holding or letting go of objects. The problem is that part of the brain which controls voluntary movement is damaged and the muscle contraction is uncontrollable (Healthcare 2000-2005; Hannover Re 2002).

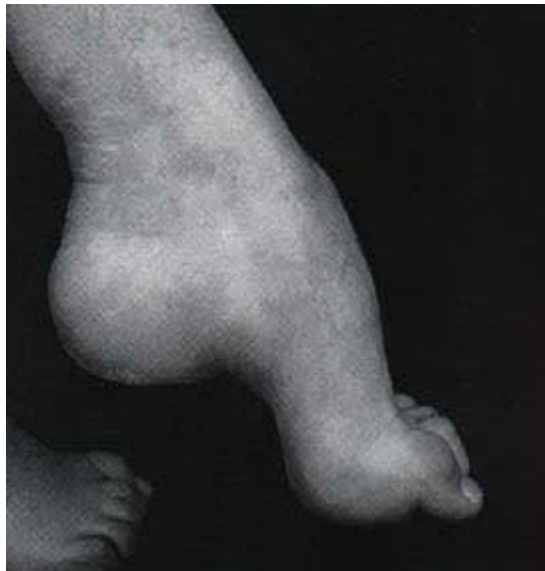
Other symptoms of spasticity may be clonus, which refers to rapid muscle contraction, exaggerated and persistent reflexes, contractures and fixed joints. When both legs have spasticity they may turn in and cross at the knees. The abnormal leg posture is called scissoring and may interfere with walking. The child may also walk on his or her toes and this is called equines (see figure 2.7). Twisted muscles may cause the child to sit with knees together and the buttocks are on the ground between the feet. The child may also have a 'chicken wing', hoarse voice, severe trembling of limbs on one side of body and unsteadiness (National Institute of Neurological Disorders and Stroke 2001; Ketonic Resources 1998).

Spasticity may involve regional and global involvement. Regional refers to some parts that are affected while global means that the whole body is affected (Pellegrino 1997:502). Spasticity may also be described according to the number of limbs involved as reflected in table 2.3 (cf. Batshaw 1997:502-5030, Tredoux 2000:30-33, Gupta 1999:9 and Ketogenic Resources 1998). It should be read in conjunction with the illustrations depicted in figure 2.6.



**Figure 2.6** Regional and global involvement of spasticity

Source: <http://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe002g/dwe00211g20.gif>



**Figure 2.7** Shortening of posterior leg muscles - ankle equinus

Types of cerebral palsy	Causes	Movement and postural problems	Associated disorders
<b>Monoplegia</b> The term “mono” means one. In monoplegia one limb is affected. This is a rare condition which may later turn out to be hemiplegia.		Movement disorders are usually mild and may disappear with time.	
<b>Hemiplegia</b> “Hemi” means half. In hemiplegia on side of the body is more affected than the other, the arm is more affected than the leg. In the brain the motor neurons which control one side of the body are located in the opposite cerebral cortex; a right-sided hemiplegia indicates injury or dysfunction of the left side of the brain and vice versa. The arm is usually held in flexion, that is, flexed or bent at the hand, wrist and elbow with clenched fist. The arm or leg on the affected side may be shorter or less developed than the arm or leg on the other side.	The main cause may be postnatal factors such as anoxia.	The difficulty experienced when moving will be noticed when the hand is used. Problems with leg movement are indicated by weight bearing and walking. The child may not be able to use the affected hand, depending on the degree of impairment and how much sensation he has in the hand. For example, children with little sense of touch or position in their arm tend to ignore the arm. About 50 percent of children with hemiplegia have some loss of sensation. The gait of the child is often accompanied by walking on toes with straight knees because of the pull at the hip. The child swings legs outward, then inwards in a broad arch.	<i>Speech:</i> may be affected because of postnatal factors <i>Hearing:</i> intact <i>Vision:</i> may be affected <i>Convulsions:</i> common <i>Intelligence:</i> is variable and severe intellectual problems are rare
<b>Diplegia or paraplegia</b> The legs are more affected than the arms. About 10 to 20 percent of the population with cerebral palsy which also suffers from diplegia.	Low birth weight, multiple births, trauma and anoxia.	The child has a good head control. Stiffness may be noticed when trying to separate the legs and rolling over. Due to stiff leg muscles the child tends to stand on or walk with toes and scissor the legs. Ambulation is often delayed. There is clumsiness in the use of the hands and arms. Some of the children have problems using the eyes and hands together, hence the difficulty they experience when writing and performing manual activities. The child with diplegia can sufficiently control the upper parts of the body, that is, the trunk, arms and head especially if the child is mildly affected. Most of the daily activities can be carried out.	<i>Speech:</i> may be slow and laboured in more severe cases <i>Hearing:</i> may be affected <i>Vision:</i> most children may have incoordination of eye movement and perceptual defects <i>Convulsions:</i> are usually not common <i>Intelligence:</i> It varies, a high proportion of diplegics are in the normal range and some are intellectually above average

Types of cerebral palsy	Causes	Movement and postural problems	Associated disorders
<b>Quadriplegia</b> All four limbs, the face and the trunk are affected. This is global or total involvement. It affects about 20 percent of the population with cerebral palsy.	The above stated causes of types of cerebral palsy also cause quadriplegia in a cerebral palsied child.	The child has difficulties in all types of movement of arms, legs, face and trunk. Tight hip adductor, and the ankles often have plantar flexion. Legs and feet have more involuntary movements than arms and hands. Some of the children are never able to walk. Children with quadriplegia have difficulties with most activities of their daily living.	<i>Speech:</i> severe problems such as dysarthria <i>Hearing:</i> severe problems <i>Vision:</i> severe problems including eye co-ordination problems <i>Convulsions:</i> may be present <i>Intelligence:</i> impairment may be present <i>Feeding:</i> there may be sucking, chewing or swallowing difficulties <i>Medical complications:</i> may be present due to the extent of their motor disabilities.

**Table 2.3** Types, causes, movement and postural problems, and associated problems

Other evidences of pyramidal or spastic cerebral palsy are, according to literature quoted above:

1. *Abnormal stretch reflexes*: this implies that tapping the elbow or knee or ankle with a reflex hammer causes the limb to extend with a stronger and faster jerk than normal.
2. *Ankle tonus*: When quick flexing the calf muscles and holding the foot upward, calf muscles quickly and rhythmically contract. Clonus (rapid involuntary contraction and relaxation of a muscle) may occur if the foot is flexed upwards or when the child is made to stand.
3. *Positive Babinski*: instead of flexing (bending inward) the toes of the foot fan out when stroked from heel to toes. This is abnormal in a child of over one year.
4. *Contractures*: Some joints tend to have abnormal shortening of muscles and tendons that limit movement around joints.
5. *Primitive and postural reflexes*: Gupta (1999:96-97) records the following
  - a) *Righting and protective reflexes*: for example, the head righting tends to appear during the middle of the first year but may not appear.
  - b) *Symmetrical tonic neck reflex*: appears for few weeks, from six to eight months in an unaffected child. This reflex may persist beyond eight months and hamper the crawling of a child. The fact is that the extension of the head stimulates the extension of arms and legs and the flexion of the head stimulates the bending of the limbs.
  - c) *Tonic labyrinthine reflex*: is an exaggerated flexion of the head which increases the extensor tone. The result is opisthotonus and dystonic posture. In opisthotonus the head and heel are bent backwards and the body bowed forward.
  - d) *Positive support reaction* is exaggerated. When the forefoot comes into contact with the ground, the extensor spasticity, adduction and plantar (sole of the foot) flexion increases.

The second type of cerebral palsy is extra-pyramidal or dyskinetic athetotic types.

#### 2.5.1.2 Extra-pyramidal or dyskinetic athetotic cerebral palsy

Athetosis refers to slow, distal and writhing movements. About 25 percent of all cases with cerebral palsy suffer from athetosis. The main cause of athetosis is damage to the cerebellum (see 2.4.1.3) or basal ganglia (see 2.4.1.2). Other causes of athetosis in children with cerebral palsy are perinatal (see 2.6.2.1), birth injuries (see 2.6.2.2) or jaundice (Hannover Re 2002; Supratentorial System 2002).

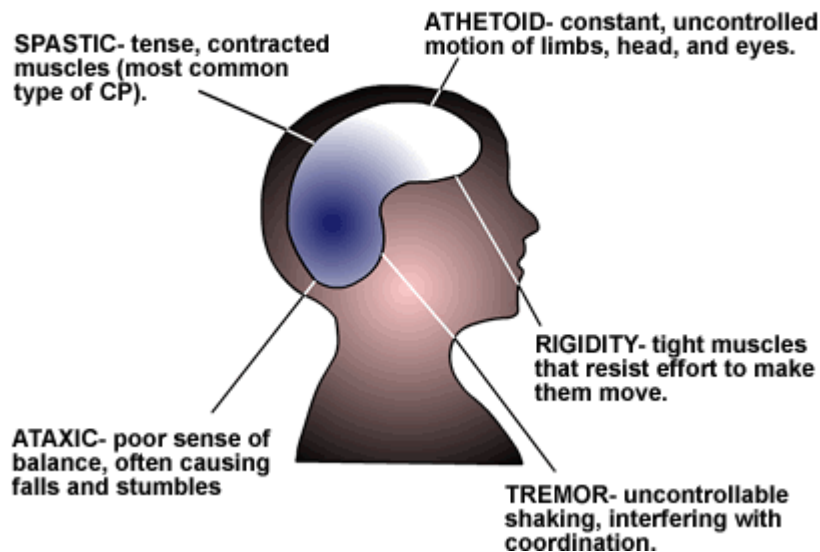


The movements of the child are affected, for example, uncoordinated movements and the disability to maintain posture. There are involuntary and purposeless movements of the face, arms and trunk. Due to involuntary flexion (bending) of the wrist and slaying (spreading) of the fingers the child may be unable to reach for objects. The presence of low muscle tone in extra-pyramidal cerebral palsy causes problems in maintaining postures for sitting and walking (National Institute of Neurological Disorders and Strokes 2001).

The associated difficulties caused by the inability to control muscles include: feeding problems that originate from involuntary grimacing and tongue thrusting, which lead to swallowing problems, drooling and slurred speech. Any stress aggravates abnormal movements while relaxation such as sleep reduces abnormal movements (Tredoux 2000:32). Medical professionals often use certain terms to refer to involuntary movements that are linked with extra-pyramidal cerebral palsy. These are:

1. Dystonia is a sudden change in axial posture because of impaired muscle tone. There are slow, rhythmic, twisting movements of the trunk or the whole arm or leg. Dystonia may also cause abnormal postures, for example, severe trunk rotation (Gupta 1999:95). According to Batshaw (1995:95), dystonia is a “rigid posturing centered in the trunk and neck”.
2. Chorea is a sudden, quick, jerky movement of head, neck, arms or legs (Gupta *ibid*).
3. Rigidity is a very high muscle tone in any position; it allows very limited movements (Cerebral Palsy and Conductive Education 2001).
4. Ataxia is a low muscle tone that is accompanied by poor coordination of movements. There are about 5 to 10 percent of children with ataxia in a cerebral palsied population. The cause of the condition is the damage to the cerebellum (see 2.4.1.3 and figure 2.8), severe neonatal difficulties, abnormal birth, meningitis and encephalitis (Hannover Re 2001).

## TYPES OF CEREBRAL PALSY



**Figure 2.8** Relation of brain damage to cerebral palsy

Source: <http://www.ecaucp.org/>

With regard to movement there is an unsteady walk with wide-based gait, feet placed usually far apart. Problems are experienced when trying to execute quick and precise movements such as writing or buttoning a shirt. There may be an intention tremor. In this type of tremor, commencement of a voluntary movement, such as reaching for an object, causes trembling to affect the body part being used. Trembling gets worse as the person gets nearer the desired object (National Institute of Neurological Disorders and Stroke 2001). Tredoux (2000:32) is convinced that “most children with ataxia are eventually able to walk”.

The third type of cerebral palsy is the mixed type. In this type some people may have some of the above stated symptoms.

### 2.5.1.3 Mixed cerebral palsy

The term mixed cerebral palsy is used when more than one disorder exists in a child with cerebral palsy and none predominates over the other. This mixed type is global because the entire muscular-skeletal system is involved. The causes of mixed cerebral palsy are damage to

pyramidal (see 2.5.1.1) and extra-pyramidal pathways (see 2.5.1.2), the basal ganglia (see 2.4.1.2) and the cerebellum (see 2.4.1.3) (Batshaw 1997:503).

Tight muscle tone of spastic cerebral palsy and the involuntary movements of athetoid cerebral palsy hamper movements of a child. Often spasticity is more obvious at first, with involuntary movements increasing when the child is between nine months and three years. The most common mixed types are spasticity and athetosis (Cerebral Palsy Facts, Information and Resources for Parents 2002). Other combinations are also possible such as spastic-athetoid-ataxia cerebral palsy (Hannover Re 2001).

The question arises: Why does a child have cerebral palsy? The answers are provided in the discussion which follows.

## **2.6 Causes of cerebral palsy**

The cause of cerebral palsy is brain damage and the cause of this injury may be due to a large number of factors. In general, two main problems give rise to cerebral palsy:

1. The developmental brain malformation, that is, the inability of the brain to develop properly.
2. Neurological damage to the developing brain of the child.

### **2.6.1 Developmental malformations**

Sometimes the brain of the developing foetus may be hampered in its developmental process. The usual number of the brain cells may not be developed. Communication between brain cells may be affected or the cells may not migrate to areas where they are supposed to be. Causes of these disruptions are mostly unknown but may include genetic disorders, abnormalities of chromosomes such as having too much or too little genetic material, or faulty blood supply to the brain. Cerebral palsy may also result from brain malformations in areas that control voluntary movement (Cerebral Palsy Facts, Information and Resources for Parents 2002; Nemours Foundation 2001).

## 2.6.2 Neurological damage

Besides developmental malformations there is also neurological damage. In this case the child has an injured brain, sustained before, during or after birth. The causes of injury are premature births, problematic deliveries, neonatal medical complications or lesions to the brain (Cerebral Palsy Facts, Information and Resources for Parents 2002). The following conditions may cause cerebral palsy in a child and are classified according to the timing of their occurrence, that is, prenatally, perinatally and postnatally. Not all factors will be discussed, only those which seem most important and which will serve as examples of how the condition originates in a child.

### 2.6.2.1 Prenatal factors

Prenatal period starts from conception to the time of labour. The incidence of cerebral palsy's prenatal causative factors is about 10 percent of all children with cerebral palsy (Tredoux 2000:34). Some of the factors include:

#### *1. Anoxia*

The term anoxia refers to the 'cut off' of oxygen to the brain and mental changes occur. Causes of anoxia may be the knotted umbilical cord or when the cord is wound tightly round the neck of the foetus. If the absence of oxygen is complete, it is called anoxia. If there is low supply of oxygen, the condition is referred to as hypoxia. Reasons for hypoxic state are the premature separation of the placenta during delivery or swelling of the brain due to illness (United Cerebral Palsy Association 2001; Adam 2001).

#### *2. Maternal illness*

The mother of the child may have had medical problems such as high blood pressure, diabetes, heart conditions, hyperthyroidism, severe asthma, toxemia, faulty implantation of the foetus, threatened abortion, foetal anoxia, maternal and foetal blood incompatibility, taking of drugs, maternal hurts in accidents, genetic factors and brain abnormalities of the foetus. The result is cerebral palsy in the child (Arthur's South Africa Cerebral Palsy Home 2001; Tredoux 2000:34).

### *3. Infections in the mother during pregnancy*

Certain intrauterine infections or viruses may cause cerebral palsy in the child. These include rubella (German measles), sexually transmitted diseases such as gonorrhea, chlamydia, syphilis, meningitis, meningo-encephalitis, tuberculosis and toxoplasmosis. Other bacterial and viral infections also attack the baby's system (Arthur's South Africa Cerebral Palsy Home 2001; United Cerebral Palsy Association 2001).

### *4. Rh incompatibility*

The name Rh- is derived from rhesus monkey where the factor was first found. The spouses whose Rh- differ may cause Rh- disease in the child. This is the case where the man is Rh-positive and the wife is Rh-negative. There will be incompatibility between the Rh-positive blood of the child and that of the Rh-negative blood of the mother. Rh-disease destroys the foetal blood cells. The result is jaundice or hyperbilirubinemia (a lot of bile in the blood stream of the child which destroys the red blood cells and reduces oxygen supply in the blood stream) (United Cerebral Palsy Association 2001; Tredoux 2000:35).

There may be also unknown prenatal factors which cause cerebral palsy in the child.

#### **2.6.2.2 Perinatal factors**

The perinatal period ranges from the onset of labour to about 28 days after birth (Tredoux *ibid*). Some perinatal factors are:

##### *1. Prematurity and low birth weight*

There is a relationship between prematurity and low birth weight. The reason is that low birth weight of 1 500 grams and a birth of a child before term may result in cerebral palsy. About 40 percent of children with cerebral palsy are born either before term (preterm) or with low birth weight (Nemours Foundation 2001; Gupta 1999:101). Sheena (2001) explains:

"When children are born prematurely, the developing brain is injured easily. Injury to the brain around the time of delivery can result from a number of different causes, most having to do with disruption of blood and/or oxygen delivery to areas of the brain. Blood flow is difficult for the premature infant to regulate and can be especially problematic under stressful conditions (such as the reduced oxygen or excess carbon dioxide likely to result from poor lung function). The cranium of the preterm infant is soft enough and the external pressure can easily change its

shape, and increased pressure within the cranium can interfere with blood flow. Severe bleeding from blood vessels can also result in decreased blood flow to otherwise uninjured areas”.

## *2. Birth asphyxia*

Lack of oxygen in the brain tissue is called asphyxia. This lack damages the brain especially at birth, during infancy and in early childhood. At birth the cause of asphyxia is a rupture of the placenta where the placenta tears loose too soon during the birth process and cuts off the oxygen supply to the baby. The result is cerebral palsy (Nemours Foundation 2001).

Gupta (1999:101) explains that asphyxia reduces oxygen in the child and carbon dioxide increases due to abnormal respiration. To cause neurological damage asphyxia must be “extreme and prolonged”. Asphyxia not only results in cerebral palsy in the child but may also cause mental retardation and epilepsy in a baby with cerebral palsy. Administering drugs to the mother to reduce pain, for example, the use of barbiturates and morphine may cause reduced oxygen. These drugs affect the respiration of the child (Tredoux 2003:35)

## *3. Medical mistakes during pregnancy*

Some medical mistakes made by doctors and nurses in hospitals may cause cerebral palsy. Cerebral Palsy Facts, Information and Resources for Parents (2002) identifies some of the mistakes as follows:

- Leaving the child in the birth canal too long causing lack of oxygen to the brain.
- Failure to recognize and treat seizures following delivery.
- Failure to detect a prolapsed cord (the umbilical cord can wrap around the child's neck, cutting off oxygen to the brain).
- Excessive use of vacuum extraction.
- Improper use of forceps.
- Failure to perform a Caesarean section in the presence of foetal distress.
- Not responding to changes in the foetal heart rate.
- Failure to respond to the mother's changing conditions, such as high blood pressure or toxemia.
- Untimely diagnosis and treatment of meningitis.

The Cerebral Palsy Facts, Information and Resources for Parents (ibid) further mentions that when hospital procedure and standard care for the mother and unborn baby are not followed, “permanent brain damage to the unborn child can occur”. Indicators of medical mistakes that cause cerebral palsy in such situations are:

- The child’s need for resuscitation (CPR) after birth.
- Immediately after delivery the child is transferred to a different hospital, or spends time in the NICU (neonatal intensive care unit).
- The child has seizures immediately after birth, or within the first 3-4 days of life.
- The child requires oxygen to facilitate breathing after birth.
- The child needs special testing after birth such as an MRI (magnetic resonance imaging).
- A specialist is called in to care for the newborn.

#### *4. Other causes of cerebral palsy prenatally*

There may be changes in air-pressure, delivery that is quick or very slow, use of high forceps or mid forceps or low forceps and breech delivery (Tredoux 2000:35; United Cerebral Palsy Association 2001).

#### **2.6.2.3 Postnatal period**

The above stated causative factors give rise to cerebral palsy during pregnancy, child birth or even during the neonatal period. The resulting cerebral palsy is referred to as congenital for it occurs around the time of birth. “However, approximately 10 percent of the cases have acquired cerebral palsy, in which cerebral palsy has been triggered by events after birth” (United Cerebral Palsy Association 2001). The following causes may occur any time between birth and six years.

##### *1. Asphyxia*

Asphyxia can occur after birth. Some authorities regard asphyxia as number one cause of cerebral palsy during this period. Three main causes of asphyxia are choking on foreign objects such as toys and pieces of food, poisoning and near drowning (Nemours Foundation 2001).

##### *2. Trauma*

In an infant cerebral palsy may be the result of a blow to the head. Injury may be caused by falls, involvement in a vehicle accident or child abuse (National Information Center for Child and

Youth with Disabilities 2001; United Cerebral Palsy 2000). “One form of child abuse is the shaken baby syndrome, in which the caretaker is trying to quiet the baby by shaking too vigorously, causing the brain to strike repeatedly against the skull under high pressure” (Nemours Foundation 2001).

### *3. Infections*

Some brain damaging infections, after birth, may be severe infections. These include, among other things, meningitis, which is the inflammation of the meninges (the covering of the brain and the spinal cord).

The cause of the inflammation is bacterial infections. The other infection is encephalitis, which refers to the inflammation of the brain itself caused by bacterial or viral infections. Any of these two types of infections may cause disabilities that may range “from hearing loss to cerebral palsy to severe retardation” (Nemours Foundation 2001). Tredoux (2000:36) adds other causes such as childhood fevers and brain abscesses.

### *4. Other causes*

Other causes may be anoxia, that is, the low supply of oxygen to the body tissues of the infant. This condition results from carbon monoxide, lead or arsenic poisoning, strangulation and lack of oxygen. Vascular or blood vessels problems such as haemorrhage (bleeding) and thrombosis (clotting of the blood) may then occur. Another cause may be neoplasm, which is a new and abnormal growth of tissue, and it may be uncontrollable and progressive. Examples of neoplasms are tumours, cysts and hydrocephalus (Tredoux *ibid*). It is also possible that unknown factors may cause cerebral palsy postnatally.

Cerebral palsy, as already hinted at in the above discussion, may be accompanied by other difficulties called associated problems.

## **2.7 Conditions associated with cerebral palsy**

The above information reveals that cerebral palsy is caused by damage to brain parts that control movement. Damage to the central nervous system indicates that other areas, besides the motor, are likely to be affected. These areas may be the child’s thinking, reasoning, communication and even sensations. Associated conditions are discussed as follows:



### 2.7.1 Intellectual impairment

The term intellectual impairment refers to the mind or intelligence and impairment refers to delayed development of the mind. About 30 percent of children with cerebral palsy have some intellectual impairment. The National Institute of Neurological Disorders and Stroke (2001) records that about one third of children with cerebral palsy are mildly intellectually impaired, one third are moderately impaired or severely impaired, and the remaining third are intellectually normal. Usually intellectual impairment is common among spastic quadriplegic children.

The main problem when assessing the intellectual functioning in cerebral palsied children is that it may be very difficult because cognition tests require motoric or verbal responses. When this has been taken into consideration, still some children with cerebral palsy may have intellectual impairment. Others may have some degree of perceptual impairment and learning disability. The implication is that a certain type of cerebral palsy influences the risk and degree of mental impairment. For example, hemiplegia, the most common type of cerebral palsy, is linked with the best intellectual results.

Another cause of intellectual impairment in a child with cerebral palsy is injury to the foetus during pregnancy because of alcohol intake, drug abuse and toxicity. Environmental causes after birth are lead poisoning, anoxia nervosa or meningitis. These causes slow down the child's rate of development and have effects on other areas such as language development (Gale Encyclopedia of Childhood and Adolescence 2002).

### 2.7.2 Seizures

Seizures are often associated with cerebral palsy. The reason is that injuries to the central nervous system of children with cerebral palsy allow abnormal nerve impulses to occur (Chico Hyperbaric Center 2001). In a population of all children with cerebral palsy one third have seizures while 50 percent of hemiplegics have seizures (Ravel 2002).

“A seizure is defined as any sudden attack of altered behaviour, consciousness, sensation or autonomic function that is produced by a self-limited disruption of brain activity due to repetitive, simultaneous electric discharges from hyperexcitable neurons in the cortex. From this initiating region, the discharge spreads and recruits neurons surrounding the seizure focus,

causing them to discharge in an excessive synchronous, periodic discharge that produce a seizure” (Batshaw 1997:554).

In an attempt to narrow the scope of chapter 2, causes of seizures will not be discussed in detail. Sanofi Syntelabo (2002) and the National Institute of Neurological Disorders and Stroke (2001) list causes as: injury to the brain, unknown causes, spontaneous seizures and factors which do not cause cerebral palsy but are believed to do so. In South Africa, especially among black communities, certain factors are believed to cause epilepsy but these beliefs lack scientific proof. These include the power of evil spirits, witchcraft, high blood pressure, touching someone who has fits and severe shock (Sanofi Syntelabo *ibid*).

#### 2.7.2.1 Relationship between cerebral palsy, intellectual impairment and seizures

There is a link between three disorders: cerebral palsy, intellectual impairment and epilepsy or seizures. This is indicated by the fact that severe and frequent fits can injure the brain and cause or even increase intellectual impairment. The five-year study of Eriksson, Erila, Kivimaki and Koivikko (1998:465, 469, 470) reveal that “epilepsy is the most frequent additional handicap in mental retardation ... which makes the relationship between the two disorders even more complex”. The authors add: “The presence of cerebral palsy is the most significant single factor in children with mental retardation ... this means that associated disabilities, mainly cerebral palsy, do not only contribute to the higher incidence and prevalence rates of epilepsy but also to the early onset and severity of epilepsy at the individual level”. The relationship between cerebral palsy and intellectual impairment is also mentioned in 2.5.1.

Another associate disorder in cerebral palsy is visual problems.

#### 2.7.3 Visual problems

The exact incidence of visual problems in children with cerebral palsy has not been recorded by most authors. Authors simply use the terms ‘most’, ‘common’ or ‘many’. For example, Pellegrino (1997:508) states that “visual impairments are also common and diverse in children with cerebral palsy”. Menacker (1997:215) records that many causes of development disabilities may also affect maturation of the visual system. Processes such as eye alignment, visual acuity and visual perception may mature slowly, partially or abnormally. Usually refractions errors, ocular

misalignment and eye movement disorders may be frequent in children with disabilities, such as those with cerebral palsy. Some of the common examples of visual problems include:

#### 2.7.3.1 Strabismus

This is a cross-eyedness case where one eye focuses on an object and the other wanders away. The reason for such wandering is the absence of proper alignment owing to differences in the left eye and right eye muscles (Tredoux 2000:39; Chico Hyperbaric Center). The incidence of strabismus among children with cerebral palsy is about 40 percent. Two types of strabismus are esotropia: the eyes turn inwards; and exotropia: the eyes turn outwards. Strabismus may be noticed in a child with cerebral palsy all the time or its presence may be intermittent when the child becomes tired. If intermittent strabismus is not attended to, it may cause amblyopia, that is, reduced or indistinct vision. Strabismus in children with cerebral palsy is corrected by eye muscle surgery (Menacker 1997:224).

#### 2.7.3.2 Diplopia

In this case there are double images. The cause is the inability of the eyes to fuse the images from two retinas properly. It is, therefore, evident that children with diplopia may encounter problems when trying to differentiate between background and foreground and may trip over objects because of errors in seeing/viewing objects (Tredoux 2003:39).

#### 2.7.3.3 Nystagmus

This is the involuntary rhythmic movement of the eyes. The movement is quick and the eye jumps from one fixation to the other, this is called saccade. The condition is caused by injury to these systems: brain stem, vestibular system or cerebellum and/or the interconnection of two or all three systems just mentioned. The result is the feeling of motion sickness in the child. The condition is diagnosed by testing the vestibular system functions (Padula & Argyris 2002).

Children with cerebral palsy with nystagmus may have underlying sensory delays that affect their balance and body awareness while moving from one place to another. Milestones in walking or climbing are likely to be affected. Parents need to be informed about visual problems in their children with cerebral palsy so that they can note problems and bring their children to the medical team.

#### 2.7.4 Hearing impairments

The concept hearing impairment refers to the inability to hear. The term can include both deafness and 'hard of hearing'. In deafness a child can hear only a few elements of speech and depends on visual hints for perceiving language. The hearing threshold of a deaf child is about 90 decibels (hearing is measured in decibels). The "hard of hearing children can partially understand spoken language. Their hearing measurement ranges from 40 to 90 decibels" (Gupta 1999:125).

Children with cerebral palsy are likely to have hearing problems due to permanent nerve damage that affects movement and may also cause a sensory neural hearing loss. Tredoux (ibid) confirms this statement by stating that "deafness or hearing loss in CP, which is associated with athetosis results from the same pathological processes as those, which cause CP itself."

The incidence of hearing problems among children with cerebral palsy is stated by the National Institute of Neurological Disorders and Stroke (2001) as follows: "Impaired hearing is also more frequent among those with cerebral palsy than in the general population. There are different kinds of hearing problems".

#### 2.7.5 Language and speech problems

Language is defined as a system of vocal, graphic and gestural symbols used to communicate needs, feelings, ideas, information and orders to other people. Speech is that part of language, which consists of spoken speech sounds. Language and speech impairment is defined as a "disorder, deviation, or delay in verbal, gestural or vocal; skills including articulation, fluency, voice quality, or language, to the extent that academic learning, social adjustment, or communication skills are hindered" (Gupta 1999:71).

It may be concluded that speech disorders suggest that children with cerebral palsy may have different types of speech and communication disorders due to, among others, neuromotor, intelligence, facial and respiratory muscles that are affected and lack of social interaction (Tredoux 2003:39).

#### 2.7.5.1 Causes of language and speech disorders

According to Borowitz (2000), muscle tone problems in the face, neck and shoulders of children with cerebral palsy may cause an oral motor disorder. This may be the indication of an inability to co-ordinate muscles for producing sounds. Speech is a motor function and children with cerebral palsy may also suffer from language problems.

It is likely that the enormous effort may cause articulation deviations, laboured, indistinct, slurred, distorted consonants and omitted sounds. The quality of the voice may be tense.

The speech of the child with athetosis (see 2.5.1.2) is slurring in rhythm and changes pitch. The excessive, involuntary movements are likely to distort sounds and may cause the voice to lack force because of disturbed respiration. The speech of the child with ataxia may lack proper articulation. Language problems may differ as reflected by the discussion that follows.

#### 2.7.5.2 Types of language problems

Two main types of language disorders are noticed among children with cerebral palsy: expressive and receptive language disorders. Expressive language disorders refer to the difficulties in expressing thoughts and ideas. If children have difficulties in understanding the language, the condition is called mixed receptive-expressive language disorder because it is rare to have only a receptive language disorder (Wang & Baron 1997:283).

The discussion on speech disorders shows that cerebral palsied children may have different types of speech and communication disorders due to neuromotor problems, intelligence, facial and respiratory muscles which are affected and the lack of social interaction (Tredoux 2000:39). Other problems are sensory and perceptual impairments.

#### 2.7.6 Sensory and perceptual problems

Children with cerebral palsy may have injuries to the parietal lobe (see figure 2.3). This part of the brain is responsible for interpretation and use of information from the senses. These children may have sensory problems and the term used for such problems is agnosia. Examples of the senses that may be affected, (Lynch & Batshaw 1997:304) are touch, pain, smell and temperature sensations.

Children with cerebral palsy seem to experience mostly problems linked with touch, position, movement and balance. The difficulty of perceiving and identifying objects using the sense of touch is called stereognosia (National Institute of Neurological Disorders and Strokes 2001). Children with cerebral palsy have two types of touch problems: tactile hypersensitivity and tactile hyposensitivity. Hypersensitivity refers to the abnormal sensitivity to being touched, for example, kissing a child may cause him or her to cry. Those with hyposensitivity have an abnormal sensation to touch and seem to be insensitive to pain. Most children with hemiplegia have sensory problems on the affected side. If the child has difficulty in planning movement, the term used is dyspraxia.

#### 2.7.7 Learning problems

The above stated associated disorders may cause a child with cerebral palsy to have difficulty in learning. Borowitz (2000) records the incidence of learning problems. About one-fourth to one half of children with cerebral palsy has a learning problem. It may be a learning disability if they have trouble with one or two school subjects but have no problem in learning other subjects. If they have intellectual impairment, the learning problem may be more severe, causing them to learn at a slower rate.

#### 2.7.8 Feeding and nutritional problems

More than 90 percent of children with cerebral palsy have oral motor dysfunction. Feeding and nutritional problems can be defined as “difficulty with eating and swallowing” (Ravel 2002; National Institute of Neurological Disorders and Stroke 2001).

The causes of feeding and nutritional problems are abnormal co-ordination of the tongue, lips and cheeks. Other causes are bite reflexes, infant swallowing styles and delayed closing of the mouth especially in children with athetosis because of reverse tongue action and oral-face movements (Tredoux 2000:38; Ravel 2002).

The results of feeding and nutritional problems are (Ravel 2002):

- a) Drooling which is due to a poor and disorganized swallowing pattern.
- b) Abnormal co-ordination which leads to poor dental alignment and periodontal problems.

Ravel (stated above) further states that children with cerebral palsy who also suffer from intellectual impairment (see 2.7.1) often practice damaging oral habits such as bruxism which is the clenching, grinding and gnashing of teeth and rumination which refers to re-chewing of previously ingested food. This habit causes stomach acids that have travelled into the mouth to bathe teeth in acid. Rumination leads to demineralisation and loss of tooth structure. Intellectual impairment also leads to pouching. In this case food or medication is kept between the cheek and teeth for a long time. This can cause dental decay. Another practice of children with cerebral palsy who are also affected by intellectual impairment is pica. This is the compulsive eating of non-edible substances such as sand, dirt and paint chips. This practice causes the destruction of tooth and damages oral soft tissue.

Another result of feeding and nutritional problems is poor nutrition. This condition renders “the individual to be more vulnerable to infections and cause or aggravate ‘failure to thrive’ – a lag in growth and development that is common among those with cerebral palsy” (National Institute of Neurological Disorders and Stroke 2001). Feeding problems of children with cerebral palsy may be eased by the work of team members.

Some children with cerebral palsy may also suffer from behaviour problems.

#### 2.7.9 Attention deficit hyperactivity disorder (ADHD)

Pellegrino (1997:510) confirms that “behaviour and emotional disorders play an important role in the lives of children with cerebral palsy and their families. Behaviour disorders range from attention deficit/hyperactivity disorder (ADHD) to self-injuries behaviour”.

Attention deficit hyperactivity disorder is defined by the National Institute of Mental Health (2001) as “distracted by unimportant sights and sounds, your mind drives you from one thought of activity to the next. Perhaps you are so wrapped up in a collage of thoughts and images that you don’t notice when someone speaks to you”.

This problem can be defined as an emotional or behaviour disorder. In the past descriptive names were used for this disorder such as hyperkinesis, hyperkinetic syndrome and hyperkinetic child syndrome. Other names which were used to refer to organic disorder were minimal brain damage, minimal cerebral dysfunction and minor cerebral dysfunction. The term

that has evolved due to better understanding of the disorder is attention deficit hyperactivity disorder/ADHD (Blum & Mercugliano 1997:449).

The incidence in a non-disabled population is indicated by Morris (2001:14) in the Daily Dispatch of Friday, November 16 (2001:14) as three percent of girls and six percent of boys worldwide. It may be deduced that among children with cerebral palsy this disorder is likely to be higher because of brain damage. The cause of attention deficit hyperactivity disorder in children with cerebral palsy may be prenatal exposure to lead, alcohol, prematurity, low birth weight at term, brain infections, inborn errors of metabolism, genes, labour complications, delivery problems and many other factors (Blum & Mercugliano 1997:450-452). These factors have already been indicated as also causing cerebral palsy in children.

Signs indicating attention deficit hyperactivity disorder include developmentally unsuitable levels of attention, lack of concentration, haphazard activity, distractibility and impulsivity. Children with this problem tend to have functional impairment in various settings such as home, school and peer relationships. This condition also affects academic performance, vocational success and social development of the child with cerebral palsy (National Institute of Health 2002).

## **2.8 Prevention of cerebral palsy**

Adam (2001) warns that “in most cases, the injury causing the disorder may not be preventable”. However, some authors are convinced that measures of prevention are increasingly possible nowadays. The United Cerebral Palsy (2000) and Cerebral Palsy Facts, Information and Resources for Parents (2002) provide the following advice:

### **2.8.1 Prenatally**

- Mothers should strive for optimal well-being before conception and receive sufficient prenatal care.
- Pregnant mothers should be routinely tested for the Rh- factor. If they are Rh-negative, they can be immunized within 72 hours after giving birth or after the pregnancy has been terminated; in this manner, preventing blood incompatibility in subsequent pregnancies.
- Blood transfusion of the foetus can also be done through the umbilical cord.
- Prevention of prematurity.



- Reduction of exposure of pregnant women to virus and other infections, for example, by vaccinating them against measles before pregnancy.
- Recognition and treatment of bacterial infection of the woman's reproductive and urinary tracts.
- Avoiding use of unnecessary X-rays, drugs and medications.
- Control of diabetes, anaemia and poor nutrition.

### 2.8.2 Perinatally

- Use of phototherapy for newborn infants with jaundice. Phototherapy, which is the exposure of the infant to the special blue lights, breaks down bile pigments and reduces its brain injuring tendencies.
- Blood transfusion can also be done in the baby.

### 2.8.3 Postnatally

- Protection of infants from injuries and accidents.
- Giving the infants sufficient care.
- Cessation of the abuse of children.

It can be added that “despite the best efforts of parents and physicians, however, children may still be born with cerebral palsy. Since in most cases the cause of cerebral palsy is unknown, little can currently be done to prevent it” (National Institute of Neurological Disorders and Stroke 2001).

The discussion so far has revealed that some children with cerebral palsy need to be assisted and trained. They, therefore, receive help in the form of support services.

## 2.9 Support services

The preceding discussion on cerebral palsy has exposed it as a complex condition. Children, therefore, need to be diagnosed before being declared cerebral palsied cases and before receiving assistance. The researcher in this study lives among the Xhosa, some of whom have cerebral palsied children. When some parents first notice that something is wrong with their

child, they consult traditional healers and thereafter Western medical practitioners. Both types of healers first try to diagnose cerebral palsy using the following criteria:

#### 2.9.1 Methods used by traditional healers in diagnosing and treating cerebral palsy

Semela (2001:128-134) in research done in the Western Cape Province in South Africa, reveals that among blacks, especially the Xhosa and Zulu speaking groups, some children are diagnosed and treated by traditional healers. Traditional healers, also of other ethnic groups in South Africa, use these procedures:

##### 2.9.1.1 Causes of cerebral palsy

- Perinatal causes resulting in brain damage occurred due to conflict between the family and their ancestors.
- Both God and the ancestors wished to reduce the tempo of parental activities and did this by giving them a child with cerebral palsy.
- Through their children with cerebral palsy parents would stay close to the natural course of events, hence such children's presence in the family.

##### 2.9.1.2 Treatment of cerebral palsy

- Pleading, by families, to the ancestors for harmony, peace and stability with the universe. The result will be a fair prognosis of the child.
- Use of animal blood to plead for clemency and appease ancestors.
- Rituals are performed, for example, skin may be used to make a temporal bracelet which the child wears.
- Not only the child with cerebral palsy but the whole family may undergo healing.
- Blessed water is drunk or sprinkled on their premises or is used for divining or for bathing the child. Water is regarded as a powerful weapon to overcome evil spirits. Water is, therefore, used for preserving peace and harmony.

Semela (2001:133) states that there is no scientific evidence in traditional healing of cerebral palsy. It is, however, "apparent that traditional and faith healers have had significant success in providing support systems for families with brain damaged children". Semela (quoted above) is convinced that traditional healers "excel in filling the vacuum that is created by the fear of the

unknown... Traditional healers are readily accepted and understood by black communities as they have the same or similar cultural and African religious background”.

## 2.9.2 Western methods

### 2.9.2.1 Criteria

Sheena (2001) states the criteria as follows:

1. Movement of muscles has to be adversely affected.
2. The motor impairment has to be due to neurological injury, that is, the source of the problem must be at the level of brain functioning, rather than being due to a problem with another part of the body such as the spinal cord or muscle.
3. The injury or lesion must be static, that is, not getting worse, but no longer resolving.
4. The injury has to occur while the motor system is still developing, usually before, during or right after birth.
5. The impairment in movement does not resolve with time.

### 2.9.2.2 Diagnosis of cerebral palsy

#### *1. Observation*

Parents and medical doctors may notice certain symptoms in a child which indicate that something is wrong even during the first few months after birth.

Brain damage according to Cerebral Palsy Facts, Information and Resources for Parents (2002) may be shown by, for example:

- Lethargy or lack of alertness.
- Irritability or fussiness.
- Abnormal, high-pitched cry.
- Trembling of the arms and legs.
- Poor feeding abilities such as the problem of proper sucking and swallowing.
- Low muscle tone.
- Abnormal posture such as the child favouring one side of the body.

- Seizures, staring spells, eye fluttering and body twitching.
- Abnormal reflexes.

Cerebral Palsy Facts, Information and Resources for Parents (quoted above) goes on to report that six months after birth, brain injury may be indicated by muscle tone and posture such as:

- Gradual change of muscle tone from low to high tone, that is, a floppy child becomes very stiff.
- The child holds the hands in tight fists.
- Movement becomes asymmetric where one side of the body moves more freely and easily than the other side.
- Problems in feeding where the child's tongue pushes food out of the mouth forcefully.

Other signs, as exposed by United Cerebral Palsy Association (2001) are:

- Poor muscle control and lack of co-ordination.
- Inability to control bladder and bowels. This is called incontinence.
- Difficulty in speaking.
- Difficulty in concentrating which has adverse results in learning.
- Trouble in interpreting sense perceptions such as the inability to identify objects by touch.
- Other problems with the senses, especially hearing and vision.

The United Cerebral Palsy Association (2001) record that most children with cerebral palsy are diagnosed by the age of five. The benefit of early diagnosis is that the child's problems can be minimized by receiving therapy, that learning is not hindered and that the child and parents can readily adjust to the disorder.

Besides the observation of the child, doctors use some of the following tools to confirm their diagnosis.

## 2. Tests

Medical doctors may examine the child by looking for slow development, abnormal muscle tone and unusual posture to rule out other disorders which cause abnormal movements. The doctors

also determine if the child's condition is not progressive. A number of tests are also used to assist in the diagnosis of cerebral palsy (Cerebral Palsy Facts, Information and Resources for Parents 2002). Not all tests will be discussed; only those which will serve as examples of tests used by doctors.

a) Ultrasonography

This instrument is used for foetal and neonatal screening. It reveals gross malformations of the brain and abnormalities caused by haemorrhage in the brain (Pellegrino 1997:501).

b) Computed tomography or CT

This imaging technique uses X-rays and the computer to reveal an anatomical picture of the brain tissues and structure. The scan shows brain areas that are underdeveloped, abnormal cysts or sacs that are often filled with liquid in the brain, or other physical problems. The value of using this scan is that doctors gain a piece of evidence indicating that the child is likely to have motor problems in the future (National Instituted of Neurological Disorders and Stroke 2001).

c) Magnetic resonance imaging or MRI

This is a new brain imaging technique. It uses a magnetic field and radio waves rather than X-rays. It gives a better picture of structures or abnormal areas which are near the bone than the computed tomography (Pellegrino 1997:501; Adam 2001).

d) Electroencephalogram or EEG

It records brain waves, showing electrical activity generated in the brain. The electrodes or special patches are placed on the head to record electric currents. The test shows the presence of seizure disorder and also tumours (Gale Encyclopaedia of Childhood and Adolescence 2001).

e) Positron emission tomography or PET and Single photon emission computed tomography or SPECT

These two instrument display pictures of the brain in colour on the monitor screen. The tests show brain abnormalities such as the presence of tumours. They complement computed tomography and magnetic resonance imaging techniques (Pellegrino 1997:501-502; Gale Encyclopaedia of Childhood and Adolescence 2001).

f) Magnetoencephalography or MEG

It measures the electromagnetic fields created between neurons as the electrochemical information is passed along. For example, when the subject under the machine is told to wiggle his or her toes, concentric coloured rings appear on the computer screen that pinpoint brain signal even before the toes are wiggled. This test is likely to reveal any disorder in the functioning of the brain. Doctors can use magnetoencephalography and magnetic resonance imaging to get the information without using surgery. This is also used to identify signals needed to control an artificial limb of the child with cerebral palsy.

### *3. Intelligence testing*

Intelligence tests are also used to find out whether the child with cerebral palsy has an intellectual impairment or not. Test results of cerebral palsied children may be affected by their associated disabilities such as in movement, sensation and speech which impede performance on these tests (Cerebral Palsy Facts, Information and Resources for Parents 2002; National Institute of Neurological Disorders and Stroke 2001).

Besides tests therapies may be used in assisting and improving the skills of children with cerebral palsy. Some of the therapies are:

#### **2.9.3 Therapies and treatments for cerebral palsy**

Cerebral palsy has its own unique associated problems (see 2.7) such as seizures (see 2.7.2), visual (see 2.7.3), hearing (see 2.7.4), language and speech (see 2.7.5), sensory and perceptual (see 2.7.5), learning (see 2.7.7), feeding and nutritional (see 2.7.8) and behavioural (see 2.7.9) problems. All these problems require a multidisciplinary team whose members may be:

paediatricians, psychologists, physical, occupational, language and speech therapists, early education and, special education professionals, social workers and neurologists (Gupta 1999:102).

#### 2.9.3.1 Orthotic appliances

Orthotic appliances are equipment used by the child with cerebral palsy to improve, for instance, motor skills. These include:

*Walking equipment* which is used to support, align, prevent or correct deformities and improve the functioning of movable parts of the body in a child with cerebral palsy. Most of the equipment is made of polypropylene. Devices include ankle-foot orthosis (AFO). It prevents plantar flexion contractures which hinder walking and cause equines deformity. It improves foot position and gait (Gupta 1999:105) (see figure 2.9). Other walking aids are strollers, wheelchairs and walkers. Other aids are special handles or grips for children who have trouble holding small objects like fork or spoon. Eating equipment may be adapted to the needs of the child such as a curved or bent spoon. The same applies to the holding of pens and pencils (Cerebral Palsy Facts, Information and Resources for Parents 2002).



**Figure 2.9** Gait Correcting Orthosis

Source: [http://www.davidhartclinic.co.uk/the\\_system.html](http://www.davidhartclinic.co.uk/the_system.html)

*Communication aids* for communication problems include a book, poster or pictures which show what the child wants. Children may also use alphabet boards to spell out their messages. Nowadays computers are used by children with cerebral palsy for communication (Cerebral Palsy Facts, Information and Resources for Parents 2002).

#### 2.9.3.2 Education

Schooling is the major instrument which enables the child to enter into the wider community. Some children are offered specialised education due to their problems. This type of education addresses the educational needs of such children.

In other countries children with cerebral palsy and their families are provided with programmes such as early intervention pre-school specialised education and individualized programmes to address their special needs. They also receive multidisciplinary team assistance (see 2.9). In South Africa Clarke (2002) advises that 'special' and 'ordinary' systems of education should be integrated. The reason for such advice is that in South Africa children with disabilities are mostly accommodated in 'special schools'.

Another area that requires attention is the plasticity of the brain.

### 2.10 Plasticity of the brain

Some of the needs of the child with cerebral palsy require therapeutic services (see 2.9) and special education (see 2.9.3.2) early in life. The reason can be found in the plasticity of the brain. Cerebral Palsy Facts, Information and Resources for Parents (2002) define plasticity as the ability to recover completely or partially after an injury. The brain of a very young child has a greater ability to repair itself than that of an adult. Usually undamaged areas of the brain may take over functions of damaged areas.

ScienceDaily Magazine (2002) confirms the plasticity of the brain by stating that "one key factor in recovery time ... is whether white matter has been damaged. White matter consists of myelinated neuronal axons that serve as cables linking the different areas of the cortex. When these are injured, vital connections needed to allocate functions elsewhere are lost". This magazine continues to reveal that "contrary to long-held popular belief, our brains may not only



produce new brain cells or neurons throughout life, but the newly generated neurons quickly become involved in the formation of new memories – a fact that may have positive implications for the recuperative powers of our own brains when damaged by stroke or other disease or trauma”. All this, the source claims, is revealed by functional magnetic resonance imaging or MRI.

EurekAlert (2002) adds that primitive neural cells move to injured areas and attempt to form new neurons. In future, understanding how self-repair occurs could lead to reduced brain damage caused by strokes and neurodegenerative diseases.

### **2.11 Prognosis for the child with cerebral palsy**

Predicting what a child will be like, will do and will not do is called prognosis. Predicting what a young child with cerebral palsy will be like is not easy especially for the infant under six months of age. It is only at the age of two that the doctor can decide whether the child is hemiplegic, diplegic or quadriplegic. Children with cerebral palsy do not stop performing activities learned. If they regress by losing the skill, it is not cerebral palsy that causes regression. Moreover, the intellectual abilities of such children determine their prognosis. It can also be added that intellectual impairment (see 2.7.1) affects the children’s functioning (Alfred Dupont Institute 2001).

With regard to life expectancy, the population with cerebral palsy may be less than that of the general population with exceptions. Prognosis differs according to each type of cerebral palsy. For example, “children with a mild hemiplegia probably will have a typical life expectancy, while a child with quadriplegia may not live beyond age 40” (Pellegrino 1997:523). Pellegrino (just quoted) goes on to say that the strengthening of support to families, improving schools, increasing chances of employment and changing of social attitudes may be as valuable for children with cerebral palsy, as therapy and medical interventions.

### **2.12 Synthesis**

The main aim of chapter 2 was to investigate the phenomenon of cerebral palsy and the existing support services. The analysis of cerebral palsy from the physical perspective reveals the following facts:

- Cerebral palsy is a developmental disability.
- It results from the damage to or malfunctioning of the developing brain.
- There are different types, degrees and causes of cerebral palsy.
- The condition tends to have its specific associated disabilities such as intellectual impairment or affected senses (tactile, visual, and auditory).
- The nature of cerebral palsy causes the affected individuals to have special needs (also see chapter 3).
- Cerebral palsy can sometimes be prevented.

### **2.13 Projection of chapter three**

Cerebral palsy, as revealed by chapter two, tends to create problems for cerebral palsied children. Such children may, therefore, have special needs. Chapter 3 examines the needs of children with cerebral palsy.

## **CHAPTER 3: INCLUSIVE EDUCATION IN SOUTH AFRICA WITH SPECIAL REFERENCE TO LEARNERS WITH BARRIERS TO LEARNING SUCH AS THOSE WITH CEREBRAL PALSY**

### **3.1 Introduction**

In the past South Africa had a dual system of education, namely, education for learners with barriers to learning and mainstream education. Learners with barriers to learning were regarded as those having, as Gordon (2000:2) states: physical, sensory, intellectual, developmental or other differences. It was believed that they needed special educational assistance and were accommodated in so called special schools.

Events internationally and nationally have, however, paved way for the accommodation of learners with barriers to learning in ordinary schools. The focus in chapter 3 will, therefore, be on events and other factors, which paved way for the education of learners with barriers to learning, such as cerebral palsy, in ordinary schools especially in South Africa.

The discussion of the historical basis is essential because it shows how special education for learners with barriers, such as cerebral palsy, has contributed towards the emergence of inclusive education universally and nationally. It also encourages a better appreciation of inclusive education.

A brief history of the development of inclusion in Scandinavia, the United States of America, and Great Britain will be discussed. They serve to represent an international scenario of the origin and development of inclusive education. The history of inclusive education in South Africa will also be examined. Some factors, which paved way for the inclusion of learners with barriers to learning in ordinary schools, especially learners with cerebral palsy, will be dealt with.

According to Tuli (2000), factors, which played a major role in the education of learners with cerebral palsy, are the government, the corporate sector, community and family, educational institutions, social agents and the media. Tuli (ibid) explains how these factors function when promoting inclusive education in a country:

- The government provides a free environment, technical support, financial assistance, supportive legislation, mobility aids and appliances and research.
- The corporate sector supplies technical training, employment and sponsorship.

- The community and family encourage acceptance and promotion for social integration. It is also involved in inclusive schools.
- Inclusive schools' instruction provides equal opportunities in academic, sports and vocational training.
- Social agents promote inclusive education through financial assistance, networking and advocacy.
- The role of the media is to create positive public opinion and the inclusion of success stories about learners with barriers to learning.

The limited scope of chapter 3 allows only some of the above stated factors to be discussed. The focus will firstly be on the historical development of inclusive education in these countries:

## **3.2 First world countries**

### **3.2.1 Scandinavia**

Scandinavian countries such as Sweden, Norway and Denmark are regarded as pioneers in the field of inclusive education. During the 1960's parents of learners in these countries objected to the exclusion of their learners with barriers to learning from ordinary schools (Sidogi 2001:56, Gordon 2000:3).

### **3.2.2 The United States of America**

#### **3.2.2.1 Historical perspective**

Authors such as Sands, Kozleski and French (2000:18-19) state that Itard (born in 1775; died in 1883) wrote a book titled "The wild boy of Aveyron". In this book he describes the condition of a 12-year-old boy who had been abandoned in the woods in the south of France and grew up there. The boy had no language and social skills. Itard taught the boy. His educational efforts are recognized, at least in America, as the beginning of education for learners with barriers to learning. Itard's educational efforts were an incentive to American educationists. They had established, by mid-1800s, schools for learners with barriers to learning in the United States.

Since that era the government or local or charitable organizations founded schools for learners with barriers to learning. By 1952 law enforced the education of learners with intellectual

impairments, especially those with moderate or severe to profound levels. These learners were excluded from ordinary schools. They were accommodated in state-run residential institutions.

### 3.2.2.2 Roles played by federal laws

A number of federal laws provided guidance on how learners with barriers to learning should be identified, assessed, accepted in ordinary schools and taught. Examples of public laws were those of 1952 and 1975. The 1975 law, due to its importance, was re-authorized several times: in 1986, 1990, and 1997 (Smith, Polloway, Patton & Dowdy 2001:12-13).

The Public Laws, as recorded by Smith et al (2001:12-13), Wood (1998:8) and Turnbull et al (1999) created suitable conditions for learners with barriers to learning. This implies that learners could access general education programmes. Schools sought out and implemented suitable educational services for learners with barriers to learning. Schools provided appropriate individualized services to learners with barriers to learning. Suitable educational services were provided in the least restrictive environment. Parents actively participated in inclusive educational processes. Learners with barriers to learning were educated together with their non-affected peers. Proper management, auditing requirements and educational procedures for learners with barriers to learning were established. Federal funds were used to finance educational efforts of state and local government. Learners with barriers to learning obtained a right to a free appropriate public education (FAPE). Learners with barriers to learning also received non-discriminatory evaluation procedures, procedural due process, individualized education programme (IEP) and learned in the least restrictive environment (LRE).

Laws transformed education for learners with barriers to learning into a service and not a setting where such learners were sent. Families were provided with an individualized family service plan (IFSP). This type of plan contained information on the progress of learners with barriers to learning. It also contained suitable services, which could be useful. The adolescents and young adults received an individual transition programme (ITP). Parents also received the IFSP and ITP. The personnel of the community, rehabilitation and vocational services assisted in ITP's construction. The ITP had to complement the IEP so that learners with barriers to learning could receive appropriate skill training and support during the transition from the school to work situation. Social adaptation programmes were also drawn up.

The situation in Great Britain with regard to the history of inclusion was as follows:

### 3.2.3 Great Britain's historical perspective and laws on inclusive education

Wearmouth (2001:ix), Dyson and Millard (2001:1-2) Farrell and Ainscow (2002:1) and Horsfall (2003) state that the British citizens, like those of the United States of America used laws to effect educational changes and the implementation of inclusive education. The laws contributed as follows:

- The British Elementary Act of 1870 and the Scottish Act of 1872 enforced compulsory education of all learners. Two types of education systems were the result, namely, the ordinary and the education for learners with barriers to learning.
- The 1944 law gave rise to the medical model where barriers to learning were viewed as body, mind and intrinsic problems.
- The 1981 Education Act resulted from the Mary Warnock recommendations of 1978 on the education of learners with barriers to learning. This law reduced negative effects of labeling, introduced a multidisciplinary approach and provided a framework for assessment of learners with barriers to learning.
- The 1988 Education Reform Act encouraged a 'market' approach, competition, consumer choice and applied pressure on resources. Assessment was used to evaluate schools, local management of schools and enabled an open enrolment in schools.
- 1993 Education Act stressed the Code of Practice in schools.
- The 1997 Green Paper adopted the 1994 UNESCO's Salamanca Statement. Thus, all learners had a right to be in ordinary schools.
- The 2001 Special Educational Needs (SEN) and Disability Act of 2001 introduced new educational rights and new duties.

Besides the United Kingdom (see 3.2.1) and the United States of America (see 3.2.2), inclusion tendencies also occur at an international level.

### 3.3 Internationally: the 'global agenda' of inclusion

Internationally there have been some developments with regard to a 'global agenda' of inclusion. Dyson and Forlin (1999:26) and Burden (1999:17) record some of these as:

- The politicization of barriers to learning internationally and in South Africa.

- Rights of learners with barriers to learning to inclusive education.
- The World Programme of Action Concerning Disabled Persons provided a policy framework. This policy promoted effective measures for preventing barriers to learning. It also encouraged rehabilitation and the realization of goals towards full participation.
- The United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities issued standards for a national planning process.
- The rights of learners with barriers to learning were strengthened by the Charter of the United Nations of 1945 and the Universal Declaration of Human Rights of 1948.
- The United Nations Declaration of the Rights of the Child in 1959, was revised in 1989.
- The International Covenant on Economic and Cultural Rights of 1966. Article 13 stressed that education is a social right.
- In 1980s the United Nations supported inclusive education through its covenants and charters.
- The 1990 World Conference of Education for All, held in Jomtien, Thailand.
- In 1993 the United Nations drew up a document containing six rules on Standard Rules of Equalization of Opportunities for Persons with Disabilities.
- Social justice movements emerged from:

### 3.3.1 The Salamanca Statement of 1994

This was the key document in guiding inclusive movements and social justice internationally. The document, besides encourage for inclusive education, eliminates discriminatory attitudes. The document also suggests that inclusive education can reduce costs resulting from the financing of special and ordinary schools. Its guiding principles were the rights of every child to education as in the Universal Declaration of Human Rights and the World Declaration of Education for All and accommodation of all learners in schools. It also declared that human differences are normal and that learning must be accordingly adapted to the barriers of the learner.

The Salamanca Statement also suggested the Framework for Action. The framework contained the following sections:

- the new thinking in education for learners with barriers to learning
- guidelines for action at the national level

- guidelines for action at regional and international levels
- topics on diversity (Naicker 2003; Rustemier 2003; Burden *ibid*).

Due to the limited scope of chapter 3 these sections will not be discussed.

About 193 countries signed the 1989, 1993 and 1994 documents. Signing was an indication that these countries, as Rustemier (*ibid*) states, “recognize the human rights of all children to education which is inclusive”.

The Salamanca Statement, therefore, “clearly indicates that inclusion is not only about reconstructing provision for learners with disabilities, but also implies extending educational opportunities to a wide range of marginalized groups who may historically have had little or no access to schooling” (Gordon 2000:6).

### 3.3.2 The financing of inclusive education

There is a view that full inclusion – all children and young people learning together, including all disabled children – would be too expensive. Yet, the example of Mali (in Africa) demonstrates that inclusion can happen whatever resources are available. Internationally, work by both the World Bank and Organization for Economic Co-operation and Development (OECD) has shown that it is far more expensive to operate dual systems of ordinary and special education than it is to operate a single inclusive system (Rustemier 2003).

The question is: What is the best way of using finances productively in an inclusive situation? This is answered as follows:

The use of funds in a productive manner in countries such as the United Kingdom resulted in the economic growth after the Second World War. The country could then financially support public services. This implies that its citizens received free access to education, health services and other services because governments funded through taxation. However, developed countries encountered problems in funding public services due to:

- Democratic changes: a decrease in tax payments because of retrenchment of workers.
- Economic restructuring which contributed towards unemployment.



- Costs increased in services such as complicated medical treatments and in welfare benefits.
- There was a rapid population growth.
- An attempt to have the education system, which was compatible with the developed world, was affected by the use of very limited financial resources.
- Special education became too costly due to:
  - low pupil-teacher ratio
  - provision of highly trained staff
  - costly special teaching materials and equipment
  - expensive maintenance of special schools' buildings, administrative support and management
  - costly transportation over long distances of learners with special needs, especially in rural and low population areas.

Inclusive schools were then envisaged as the main solution to funding problems by states. The solution envisaged would be in the form of having learners in the same school, sharing resources and the larger school population could reduce the rising costs (Dyson & Forlin 1999:36-38).

It may be assumed that South Africa is at present experiencing the same problems in implementing the inclusive system, as those experienced by the United Kingdom when funding social services. Financial problems could also be minimized in the same way as done elsewhere.

Certain events in Africa also influenced South Africa to implement educational reforms.

### **3.4 The South African inclusive education: a brief historical perspective**

In South Africa the transformation of the education system was the result of historical events. Not all events will be discussed; a few will indicate how inclusion originated and developed.

#### **3.4.1 Historical events**

#### 3.4.1.1 The emergence of an education system for learners with barriers to learning

In 1863 this type of education began in South Africa. The Roman Catholic Church in Cape Town established the first school for deaf children. Other churches followed suit. Services were then extended and other learners with barriers to learning were catered for. The churches' efforts gradually resulted in the establishment of existing schools for learners with barriers to learning (Schoeman 2003).

In 1980 the Human Sciences Research Council was requested by the South African government to conduct research on the provision of education for learners with barriers to learning for all races in South Africa. The De Lange Commission reported back in 1981. It formulated eleven principles for educational provision in South Africa. The Commission's most essential recommendation was that equal chances for education, including equal standards in education for every inhabitant, irrespective of race, colour, creed or sex, be the purposeful endeavour of the state (Gordon 2000:5).

#### 3.4.1.2 The Freedom Charter of 1955

In 1955 progressive organizations in South Africa drafted the Freedom Charter. The document described the ideal for education in South Africa. Burden (1999:16-17) states its contents as follows:

- The aim of education shall be to teach the youth to love their people and their culture, to have brotherhood, liberty and peace.
- Education shall be free, compulsory, universal and equal for all learners.
- Higher education and technical training shall be open to all by means of state allowances and scholarships awarded on the basis of merit.
- Adult illiteracy shall be ended by mass state education plan.
- Teachers shall have all the rights of other citizens.
- The colour bar in cultural life, in sport and in education shall be abolished.

Burden (ibid) regards the Freedom Charter as a prophetic document:

- It did not only come up with statements encouraging South Africans to strive towards achieving the ideal of education for all, but sent out warning signals concerning equality and quality of education in South Africa.
- It signaled the realization that South Africa was a diverse country in which education should serve the needs of a pluralistic society.
- The Constitution of the Republic of South Africa Act 108 of 1996 confirms that the suggestions of the Freedom Charter became a reality 40 years later in the final Constitution of a democratic South Africa.

#### 3.4.1.3 Organization of African Unity (OAU)

Burden (ibid) goes on to state that the British Prime Minister, Harold Macmillan warned the South African Parliament in Cape Town in 1961 that winds of change were blowing across the African continent. This referred to the spirit of decolonisation. Moreover, the agendas of the OAU often contain issues of equality and quality in educational spheres.

#### 3.4.1.4 African Charter on Human and People's Rights of 1986, Article 17

The 1986 African Charter also encouraged change in education and society. It stated that:

- Every individual shall have the right to education.
- Every individual may freely take part in the cultural life of his community.
- The promotion and protection of morals and traditional values recognized by the community shall be the duty of the state (Burden 1999:17).

Burden (ibid) is of the opinion that “it can be concluded that an equal and quality education for all towards education implies a paradigm shift (mind shift), moving from a quantitative elitist and exclusive system towards a qualitative and inclusionary system which accommodates diversity (all learners) effectively in an equitable manner and in so doing achieves excellence”.

The above mentioned universal, African and South African documents show that education can, therefore, be regarded as the most essential human right because:

1. all people must be educated,
2. diversity occurs in any society,

3. it is a challenge and not a problem
4. it is a source of knowledge,
5. all people are accommodated within the same system,
6. all individual learners are unique and their abilities also differ,
7. every child's skills must be improved in a suitable manner and stress must be on learning; an inclusive educational approach must be adopted,
8. knowledge must be gained from learning the curriculum such as content,
9. assistance and assessment ought to be flexible and adapted to include all learners,
10. social systems need to be reconstructed so that they do not obstruct learning and development of all learners.

### 3.4.2 South Africa's policies on inclusive education

Legislation also encouraged the implementation of inclusive education in South Africa. Some of these laws are:

#### 3.4.2.1 Constitution of South Africa (Act 108 of 1996:7-15)

It contains certain laws, which refer specifically to learners with barriers to learning. Not all sections will be included here; only a few which serve as examples of provisions made by the Constitution for such learners. Some sections in chapter 2 of the Constitution reveal the following:

- Section 9 (3) – the law guarantees equality for all people and forbids discrimination based on the person's barriers.
- Section 10 protects human dignity.
- Sections 22 and 29 support the right to occupation and to basic education.
- Section 28 stipulates the rights of all children to care, basic nutrition, health care, shelter, social services and protection from malnutrition (Burden 1999:21).

Other key documents also formed the framework for transformation such as:

### 3.4.2.2 White Paper on an Integrated National Disability Strategy of 1997

The Deputy President Thabo Mbeki wrote in this White Paper's foreword (1997:i) that "the concept of a caring society is strengthened and deepened when we recognize that disabled people enjoy the same rights as we do."

The White Paper also contains, under the heading *Disability and Exclusion* (1997:2), the statement: "The majority of people with disabilities in South Africa have been excluded from the mainstream of society and have been thus prevented from accessing fundamental social, political and economic rights". The exclusion experienced by people with barriers and their families is the result of a range of factors. The White Paper (ibid) mentions:

- the political and economic inequalities of the apartheid system;
- social attitudes which have perpetuated stereotypes of special needs people as dependent and in need of care; and
- the discriminatory and weak legislative framework which has sanctioned and reinforced exclusive barriers.

Certain views in the White Paper of 1997 (ibid) affect learners with barriers to learning either positively or negatively. They either promote transformation and inclusion or hamper these two activities.

#### 1) *The medical view*

Between 1900 and 1965 a barrier to learning was regarded as a health and welfare issue. The state used to intervene through welfare institutions. The task of 'caring' for people with barriers was entrusted to civil society. The implication is that people without barriers control organizations for people with barriers. The aim of the medical discourse (White Paper on an Integrated National Disability Strategy 1997:9) is to: provide treatment, or to create alternatives to begging, or 'hiding away'. The philosophy of that period was that people with barriers were not to be hated or feared, but to be pitied or helped as part of the 'deserving poor'.

#### i) Traits of the medical theory

The medical theory has the tendency:

- a. to define learners by their barriers,
- b. to be patriarchal,
- c. categorize learners and this attitude tends to mar their personalities,
- d. regard a barrier to learning as an attribute,
- e. professionalizes them by making barriers to learning part of a learner's technical trouble,
- f. dominates special educational practices through its language of referring to body, patient, help, need, cure, rehabilitation and that the doctor knows best,
- g. the practice of conductive education on learners with cerebral palsy (Allan 1999:8).

However, Allan (ibid) states that the medical view needs to be reconstructed rather than abandoned. In this manner learners with barriers to learning may gain power "over their own bodies and health care".

Clarke (1997:8) adds that the medical view excludes the person from mainstream social and economic life because he or she is regarded as being incapable of living a normal life in the 'presence of the handicap'. Socialization occurs away from society and it complies with 'separate development' ideals.

The White Paper (1997:9) has this to say about how social exclusion, resulting from the medical view model, manifests itself:

- In the family learners as young as three years are sent off to board at schools for learners with barriers to learning.
- The barriers of the built environment at schools prevent these learners from participating in society.
- Ordinary school education is designed and planned in such away that learners with barriers to learning cannot be available to them.
- Information systems are not accessible to learners with barriers to learning in South Africa. For example, in society Sign Language is seldom used.
- Labour market and employment opportunities are hardly accessible after the graduation from school for such learners, and they become economically inactive.

ii) Some results of the medical view are that:

- It gave rise to the concept of “specialized education”. This concept “is not acceptable as it accentuates exclusion and marginalisation of learners, which eventually often results in stigmatization of learners” (Sidogi 2001:13).
- Families of such learners were affected for they were isolated from communities and mainstream activities (White Paper on an Integrated National Disability strategy 1997:9).
- It encourages dependence on state assistance, which in turn disempowers people with barriers. This has “seriously reduced their capacity and confidence to interact on an equal level with other people in society” (White Paper on an Integrated National Disability strategy *ibid*).
- It prevented people with barriers from ‘accessing fundamental social, political and economic rights’ (White Paper on an Integrated National Disability strategy *ibid*).
- Exclusion immediately results in the construction of people with barriers as “inadequate human beings who are unfit to be included in mainstream economic and social life” (Naicker 2003).

There is also another theory, the charitable view, which has had an effect on the education, especially of learners with barriers to learning in South Africa.

## *2) The charitable view*

This view regards learners with barriers to learning, as deserving pity and sympathy. This implies that learners with barriers to learning become tragic figures who need assistance. The results of this view as stated by Naicker (2003), Clarke (1999:8) and Allan (1999:8-9) are:

- Such an attitude is oppressive because it does not reveal the day-to-day reality of the majority of learners with barriers to learning. Such learners constantly struggle with challenges of, for example, finding a bus with a wheelchair lift.
- People, to overcome their fear or guilt towards learners with barriers to learning, use pity. Pity masks their aggression towards these learners.
- The learners are regarded as underachievers and therefore need institutional care.
- Teamwork is hardly mentioned such as that of therapists or teachers.

- People in authority especially the non-affected ones are decision makers. People with barriers do not participate in decision-making.

An additional view is that of the layperson's theory. It contributes to the establishment of so-called special education.

### *3) The layperson's view*

The basis of this theory is the medical and charitable discourses and people's fears, prejudices and superstitions. For example, some people felt that the causes of barriers were a punishment for wrongdoing, the results of witchcraft or because of the anger of the ancestors (Clarke 1999:8).

The results of this view are, as stated by Naicker (1999:14), Clarke (ibid) and Allan (1999:10), that they affect the learners with barriers to learning because the view encourages:

- Prejudices, hate, ignorance and paternalistic inclinations.
- The theory leads to the isolation of learners with barriers to learning because of their physical appearances, which may deviate, from that of non-affected people.
- The view strengthens the tendencies of victimizing or even persecuting learners with barriers to learning.

However, the following view promotes the rights of people with barriers.

### *4) The human rights view*

The human rights theory is based on the social view of a barrier. People with barriers developed this view which originated in the early 80's. People with barriers met and organized themselves. Their aim was to start a strong organization or civil movement, which could be controlled by people with barriers. The movement was intended to strengthen the idea of regarding the barrier as a human rights and development issue (White Paper on an Integrated National Disability Strategy 1997:10; Allan 1999:9-10).

The White Paper on an Integrated National Disability Strategy (ibid) further states that the cause of the human rights theory is the realization that the medical, charitable and layperson views



focus on discrimination of people with barriers. Segregation is the product of society, that is, it is a “socially created phenomenon”. In order to remedy the situation there must be a restructuring of society.

Some of the advantages of this model are that it removes obstacles which obstruct wheelchair users; it prevents the production of everyday equipment which cause difficulties for people with barriers; it empowers society so that people may accept and learn Sign Language; it empowers ordinary schools to accommodate diversity of their learners and it prevents segregation, paternalism and prejudices against learners with barriers to learning. It is a paradigm/mind shift from traditional views to a rights view. Individuals with barriers will thus be regarded as “equal and positive contributors to society” (Clarke *ibid*).

Naicker (*ibid*), therefore, considers a paradigm shift as revolutionary. Allan (*ibid*) adds that the rights view is characterized by self-reliance, independence and consumer wants rather than barriers. It is political but not adversarial. The fact is that it undermines the strength of the politicians because activists with barriers have called for greater solidarity within ‘the movement’, thus favouring a ‘marching to the beat of a single drum’ Allan (1999:9). It educates people through posters and by protesting against charitable events for learners with barriers to learning.

##### *5) The market view*

This theory, like some of the above stated views, encourages the exclusion and segregation of learners with barriers to learning. Allan (1999:10) goes on to state the effects of language usage of the market theory, with reference to learners with barriers to learning thus: It reinforces perceptions of individual defects. It encourages parents and teachers to seek formal acknowledgement of these. It leads to a dramatic increase in requests for statements or records. Teachers refer to learners with emotional or behaviour problems as ‘disturbed’. The implication is that such learners are outside the responsibilities of ordinary school classroom teachers. The terminology used in classifying learners with barriers to learning generates a “disciplinary technology of surveillance and control” (Allan *ibid*) to which learners with barriers to learning, parents and teachers are subjected.

It may be assumed, therefore, that views discussed above, except the rights view, affect inclusive efforts in South Africa and should be addressed. The second law which supports inclusive education is discussed as follows.

3.4.2.3 Report of the National Commission on Special Needs in Education and Training (NCSNET) and National Committee on Education Support Services (NCESS): Quality education for all: overcoming barriers to learning and development of 1997

In 1997 the Ministry of Education in South Africa appointed the National Commission on Special Needs in Education and Training (NCSNET) and National Committee on Education Support Services (NCESS). Its main duty was to investigate and make recommendations on all aspects of barriers to learning and support services in education and training in South Africa. The commission and the committee were to conduct research separately but “the comprehensive scope of barriers to learning and support resulted in a joint investigation” (Naicker 1999:16).

The duties of the NCSNET and NCESS included the terms of reference, principles, public participation and the research process. These will not be discussed due to the limited scope of chapter 3.

3.4.2.4 Education White Paper 6: Special Needs Education – Building an Inclusive Education and Training System, July 2001

The Minister of Education in this White Paper’s introduction stated that “the Government is determined to create special needs education as non-racial and integrated component of our education system” (Schoeman 2003). The Ministry intended, as stated by Schoeman (ibid), to achieve its determination by adhering to these strategies:

*1. Key strategies*

- The quantitative improvement of schools for learners with barriers to learning will be converted into resource centers and such centers will be integrated into district-based support teams. This will be done after an audit of all such schools.
- The mobilization of approximately 280 000 learners with barriers to learning and youth of compulsory school-going age who are outside of the school system.
- The designation and conversion of approximately 500 mainstream primary schools to full-service schools, beginning with 30 schools in identified school districts. These schools will be equipped and supported to provide for the full range of barriers to learning amongst all learners. Special attention will be paid to developing flexibility in teaching

practices and styles through training, capacity building and support to learners and educators in these schools.

- The general orientation and introduction of management, governing bodies and professional staff at schools to the inclusive model and the targeting of early identification of barriers to learning and intervention in the Foundation Phase. School support teams will be established to put in place properly co-ordinated learner and educator support services to support learning and teaching process at school level. Where appropriate these teams will be strengthened by expertise from the local community, district support teams and higher education institutions.
- The establishment of district-based support teams to provide a co-ordinated professional support service to schools for learners with barriers to learning, full-service schools and other essential services.
- Use of multiple intelligences and various learning styles as a framework for understanding differences.
- Injecting co-operative learning that accommodates different ability levels.
- Adapting Curriculum 2005 to meet the needs of diversity.

## *2. Other relevant matters*

- i) Time factor: The time frame of 20 years was proposed for the implementation of an inclusive education and training system in South Africa. There would be short- term steps as from 2001-2003, medium-steps as from 2004-2008 and long-term steps as from 2009-2021.
- ii) Structural and practical shifts: The education White Paper 6 (ibid) envisaged changes in these two areas.
- iii) Funding and Curriculum 2005: With regard to funding the Ministry of Education will financially support schools for learners with barriers to learning. Details on Curriculum 2005 are discussed in 3.4.2.6.

### **3.4.2.5 Lessons learned from South African inclusive education legislation**

Schoeman (2003) is of the opinion that the change from segregation to an inclusive education system is a long a difficult process. It is expensive because of the funding and human resources, which are involved in it. Moreover, inclusion has come to stay. The process of implementing

inclusive education is still in its infancy and far from being complete. However, there are lessons, which can be learned from it as stated by Schoeman (ibid) such as:

- The introduction of inclusive is very controversial and is an emotional matter.
- The existing school for learners with barriers to learning should not be dismantled before the planning for new ones has been completed and is ready for implementation of inclusive education. If dismantling occurs prematurely, it will cause confusion and uncertainties.
- Preparatory work must be done before inclusive education is implemented. Administrators and education need to be contacted because most resistance against inclusion in South Africa comes from people in ordinary school and not from schools for learners with barriers to learning.
- Non-governmental Organizations (NGOs) and community structures concerned with the education of learners with barriers to learning must be part of the process of implementation and not be marginalized. The same applies to institutions of higher learning and universities.
- When inclusive education is being implemented at the localized pilot project or national level, it should be clearly communicated. This can be done by orienting the people concerned, training them well and monitoring them closely during the implementation process and during its evaluation.
- The involvement of parents in the education of learners with barriers to learning is essential. They must be represented in the governance structures at school level and also in other school activities. Schoeman (2003) is aware that many South African parents are not actively involved in the education of their learners. Yet, the law encourages them to do so.
- The Ministry of Education has committed itself to develop education for learners with barriers to learning.

The question is: Has legislation both internationally and in South Africa brought about educational changes? This question is answered in the ensuing sections.

#### 3.4.2.6 Changes effected by legislature in inclusive education

Universally legislation has paved the way for and supported inclusive education. The result of such laws was a slow but effective change especially in connection with the education of

learners with barriers to learning. Some changes are recorded by Wood (1998:19), Lorenz (2003:4), and Farrell and Ainscow (2002:20).

### *1. General practical changes universally*

- i) Law provided and still provides a framework within which inclusion could and can be promoted.
- ii) Law has brought order where there was chaos; for example, the school receives guidance on how to go about making decision about providing education for learners with barriers to learning.
- iii) Law, by promoting inclusion, has changed the traditional aims of the school system.
- iv) Methods of teaching and testing are changing.
- v) The exercise of discipline in school in a school setting has been transformed.
- vi) There is more awareness of educational rights of parents and learners.
- vii) Civil rights concerning institutionalization are known.
- viii) In ordinary schools architectural barriers hampering movement of learners with barriers to learning are being removed.
- ix) Acknowledgement of the rights of all to free and equal education is on the increase.
- x) Labour laws are also supporting job-training rights at school level. Such laws also caused the commuting of learners who have completed their school training to and from job centers to be easier.
- xi) Technology has also become a way of life for learners with barriers to learning.

### *2. Some practical changes in South Africa*

The South African Schools Act of 1996 has brought changes in school admission practices. The Constitution demands “a public school must admit all learners and serve their educational requirements without unfairly discriminating in any way” (Constitution of the Republic of South Africa 1996:6).

The implication of this according to Bothma (2000:200) is that:

- Depending on the wishes, and based on the rights of all learners and their parents, including learners with barriers to learning, no learner may be turned away from public school if it is at all possible to accommodate the learner.

- Legally, the schools may be obliged to provide appropriate educational support services and make structural adjustments to accommodate children with special needs, in case they desire to attend ordinary schools.

Bothma (ibid) also states that: “The policy of inclusive education in South Africa is however not static. Currently, a shift is being made from referring to LSEN and ‘special needs’, to referring to the removal of ‘barriers to learning and development’ or ‘causes and effects of learning difficulties and effective learning”.

### *3. Effects of changes in the South African inclusive education system for learners without barriers to learning*

According to Wood (1998:20-23) legislation has “made possible education of learners with disabilities in a setting with their non-disabled peers. What impact has this had on these two groups?” Wood (ibid) supplies answers as indicated below, pinpointing the results of contact:

- Peers of learners with barriers to learning experience the fact that society consists of different types of people. They see this in other learners’ appearances that are different physically, intellectually and emotionally.
- Knowledge of the differences enables the learners to be mature in their adult life in that they learn to accept those who are different from them.
- Learners also acquire the ability to tolerate learners with barriers to learning.
- Literature also indicates that peers do not imitate the undesirable behaviour of some learners with barriers to learning.

### *4. Effects of changes in the South African inclusive education system for learners with barriers to learning*

- Learners with barriers to learning learn from the school community to be part of the school and to participate in its activities.
- Their learning may improve as well as their social and emotional life.
- Society may become more accountable for the education and the treatment of learners with barriers to learning.

- Related services may become part of the school life for learners with barriers to learning. Such services may be free medical, health, counseling, psychological and transport services.

##### *5. Effects of changes in the South African inclusive education system for educators*

Wood (1998:21) believes that legislation had “sweeping effects on the members of the educational field. Administrators, general education teachers, special education teachers, and support personnel have all felt massive change”.

###### *a) Administrators*

- Face problems of finding money for unfounded mandates and the allocation of resources, materials and manpower to support educators.
- They must see to it that the new technology and teaching curriculum are investigated.
- They face the changes in emotional climate caused by the presence of learners with barriers to learning in ordinary schools.
- In-service programmes undergo a change.
- They have to convince parents, learners, teachers and the community of their administrative support.
- Their main focus is on outcome-based education (OBE), so they are faced with the challenges of educational restructuring.

###### *b) General education teachers*

- The teachers must help in the development of teaching aids, individualization of all learners, diagnosis and curriculum modification.
- They must adapt to team teaching when trying to co-operate with general education teachers and teachers for learners with barriers to learning.
- Teachers ought to know how information is taught rather than what is taught.
- Their teaching is influenced by factors such as the learning styles of learners and materials used.
- The presence of learners with barriers to learning influences teachers to learn communication skills with such learners and with their parents.

- A teacher who resists change nowadays is likely to find teaching to be more difficult. Eventually such a teacher will suffer from job burnout, increased load and will be challenged by new instructional responsibilities.
- They have to acquire new skills of learners with barriers to learning from teachers of learners with barriers to learning.
- The roles of teachers for learners with barriers to learning are also changing. They are often called upon to help all children in ordinary schools.
- Such teachers must provide assessment, instructional, remedial teaching and tutorial instructions. They modify, among other things, lesson plans and inform general schoolteachers about medication needed by learners with barriers to learning.

## 6. *The family*

Legislation on inclusive education has empowers parents and they have:

- The right to their children's records at school and also possess procedural due process rights. This means that they can take the teachers and school to court and sue them.
- A right to be notified and also to give permission before learner is removed from a general class setting and placed in a special one.
- Hope that their children's quality of life is improved by the quality of education offered in an inclusive setting.
- A right to become part of the team who, together with other team members, develop a plan for their children.
- The right to offer feedback of their children's progress and this also enables parents to become involved in their child's education.
- The benefit of early intervention as legislation empowers the family to address the needs of learners with barriers to learning.



## 7. *The community*

The community is also affected when inclusive education is being introduced into schools.

- The community is exposed to and confronted with barriers to learning. The community has to be re-educated emotionally in order to be able to co-exist and co-work with individuals with barriers to learning.
- Job creation as community responsibility for schooled learning with barriers to learning is part of the ultimate inclusion process.
- Policies encourage communication between the community and the school.

In spite of all the advantages provided by legislation, in any country it is likely to have its shortcomings too.

### 3.4.2.7 Limitations of legislation in implementing inclusive education in other countries

In the United States of America it was only as late as 1997 that certain flaws were realized when implementing inclusive education. The flaws were the result of the findings of the National Council on Disability in 1995. Examples of flaws were low expectations concerning learners with barriers to learning and barriers to learning education programmes and insufficient focus on applying research-based proven methods of teaching and learning for such children.

Farrell and Ainscow (2002:20) are of the opinion that laws promoting inclusive education can be beneficial and simultaneously have limitations. The example, which is quoted here, represents the shortcomings of education laws in other countries. The Code of 1994 in England has been selected and it reveals limitations such as the following:

- It guaranteed nothing for the schools and Local Education Authorities had “considerable scope for the exercise of ‘judgement’, which may be guided but not governed, by explicit criteria”.
- Decisions were not made on the basis of the learners’ barriers. Different stakeholder applied different criteria to similar situations.
- The school and the Local Education Authorities had, in practice, a limited range of provision of individualized assessment.

- Schools and the Local Education Authorities adhered to the Code's rules but reached different conclusions about how to meet the barriers of learners. This means a method used to meet the barriers may not have been effective for individual learners.

Farrell and Ainscow (ibid) conclude by stating that the Code may well have “brought order out of chaos. It has, however, also brought a different kind of chaos of its own”.

### 3. 4.2.8 South Africa legal flaws with regard to inclusive education

Educational laws in South Africa also have their own limitations. Kato (2003:12) in the Daily Dispatch, the Eastern Cape Newspaper, states the following:

- Payments of school fees by learners from disadvantaged backgrounds should not be enforced because there are no funds due to poverty and lack of employment.
- Kato indirectly implores the education laws to stop ignoring the introduction of feeding systems at schools. Some children have been known to collapse during morning assemblies because of hunger.
- Laws do not fully enforce free education funded by the Education Department, for example, parents and children have no money to buy flip files for their children's portfolios. With regard to this situation Kato asks the question: “What does the government want the teachers to do in this case? Use their own money to buy files...Revise your system”.

According to Williamson and Lemmer (2003:138) the early implementation of Curriculum 2005 resulted in problems such as:

- Educators, especially in rural areas, did not have access to training materials.
- In-service training efforts did not succeed because of lack of trained facilitators.
- Educators did not know the terminology of outcomes-based education (OBE).
- The whole project was affected by lack of finances.

A Review Committee was established on 8 February 2000 under the chairperson, Professor Linda Chisholm. It had to investigate and submit findings on Curriculum 2005 by 31 May 2000. It submitted its “incisive recommendations while retaining strong support for the principles of outcomes-based education” (Chisholm 2000:18).

Anthony Hazell, the spokesman of the Democratic Alliance, reported on Matrics (Grade 12s) results in the Daily Dispatch (2003:1). He complained that “there is lack of job creation on the government’s labour legislation... current curriculum did not prepare young people for the requirements of the workplace... Most learners studied subjects they did not follow in their career”.

The Eastern Cape Department of Education’s Newsletter (2001:1) reports that “Curriculum 2005 has been revised. Teachers in the Foundation Phase will implement this revised curriculum... from 2004. Intermediate phase teachers will follow in 2005”. This curriculum will be phased in between 2006 and 2008 in the Senior phase, and was referred to as the Revised National Curriculum Statement or RNCS. It is now simply known as the NCS or National Curriculum Statement.

### **3.5 Addressing barriers to learning and development at school level**

#### **3.5.1 Activities to be undertaken**

Actions such as preventing, minimizing or removing the barriers may address the barriers of learners with learning problems. Such barriers need to be identified, for example, by studying the family and personal history of the child, his or her background situation, observation of behaviour, developmental milestones, performance and other areas needing to be identified in class or outside the classroom (Burden 2000:36-39).

Burden (ibid) goes on to say that there are tools, which can be used to collect information. These include checklists, questionnaires, interviews, and consultations, studying of reports and studying the child’s portfolios. The respondents may be teachers, principals, caretakers, parents and community members.

The best methods to address barriers to learning in South Africa would involve a plan of action to redesign and re-shape school buildings which hamper free access and the identification of factors which encourage inclusion such as a welcoming and supportive environment (Lazarus, Daniels & Engelbrecht 1999:45).

### 3.5.2 Ways of implementing inclusive education in South African schools

Burden (2003:36-39) is of the opinion that inclusive education may be implemented by using certain methods. These include “the changing of policies, attitudes, behaviour and combating ignorance by educating all participants and by transforming management structures”. Burden (ibid) mentions some obstacles that prevent changes such as negative attitudes at school, unchanging management styles, lack of in-service training for teachers and lack of materials and human resources. Due to the limited scope of this chapter the method and obstacles will not be discussed.

## 3.6 An inclusive classroom for learners with cerebral palsy

### 3.6.1 The teaching and learning of children with cerebral palsy in class

Some factors affect the implementation of inclusion in the classroom. Chapter 2 has indicated that cerebral palsy may interfere with the learning and development of the learner with barriers to learning. Barriers do not necessarily imply that learning does not occur. Even learners with the most severe barriers to learning learn by responding to stimuli in the environment. The barriers to learning may mean that a learner spends a longer time mastering a particular way of interacting with the environment or practising a particular skill many more times than his or her peers. Sometimes barriers to learning may mean that learners may not be able to learn a specific skill without direct instruction, even though he or she may be perfectly capable of learning other skills that are not part of the school curriculum (Sands, Kozleski & French 2000:151).

### 3.6.2 Meeting problems and behaviour problems of learners with cerebral palsy in an inclusive classroom

The learner with cerebral palsy is likely to present certain behaviours in an inclusive classroom. These behaviours are tabulated by Horsfall (2002) as follows:

<b>Problems of learner with cerebral palsy</b>	<b>Behaviour in inclusive classroom</b>
Communication and interaction difficulties	Speech and language problems. There may also be autistic spectrum disorders.
Cognition and learning difficulty	Global learning difficulties, specific learning problems.
Emotional, behaviour and social difficulties	A range of behaviours relating to social, psychological and environmental problems.
Sensory and physical problems (specific disabling conditions)	A range of conditions relating medical, physical, physiological and neurological factors.

**Table 3.1** Some behaviours that may be exhibited by a learner with cerebral palsy in an inclusive classroom

The teacher in an inclusive classroom may encounter some of these problematic behaviours. An example of such a situation is stated by Bayliss (European Electronic Journal 2003) and Horsfall (2002).

One of the learners in class had a left-hand hemiplegia (see table 2.3). He could not cut paper using a pair of scissors during a mathematics lesson. During school teaching practice the student teacher who had the learner in class explained to her visiting lecturer that the boy “works hard but sometimes he is lazy and has to be pushed”. When the visiting lecturer pointed out his cerebral palsy the student teacher replied that her supervising teacher at that school had not informed her. The student teacher did not know that the boy was receiving assistance from the school’s special needs provision.

Moreover, the affected right hemisphere caused problems in perception. The boy needed to be helped with visual-motor co-ordination. The cutting of paper required visual-motor co-ordination and spatial perception. The boy’s difficulty did not result from laziness but from his cerebral palsy but the student teacher had judged him as lazy. If the student teacher had had knowledge of cerebral palsy and its effects, she would have noticed:

- the weaker left arm which he ‘carried’ throughout the lesson was a sign of cerebral palsy;
- the boy’s right hemisphere cerebral palsy affected his visual perception;
- tasks requiring articulated perceptual skills were causing a learning problem;
- directed teaching did not improve the learning difficulty of the learner;
- she could have changed the task or the way the learner was expected to complete the task.

These five points indicate that there ought to be equilibrium between teaching styles, support and the learning of the child. Education for learners with barriers to learning, therefore, arises out of the interaction between these three variables. The learner experiences learning problems when he or she is prevented by cerebral palsy from performing tasks or from learning those things his or her peers are capable of learning.

Bayliss (ibid) continues to state that not only the teacher must understand the learner's cerebral palsy. The learner must also understand:

1. cerebral palsy,
2. the psychology of his or her needs,
3. how cerebral palsy affects learning.

Such knowledge will assist learners because it will:

- Point the way to more efficient learning.
- Meet their needs through changed teaching styles where there will be a one-to-one working situation for brief periods.
- Encourage them to request the teacher's assistance if required. If a learner cannot cut, the teacher can change the task and devise another, which the learner can do. The boy could, for example, be given a jigsaw and build the mathematical shapes required. In this manner the learner with cerebral palsy is not be overlooked.

The teacher can also gain knowledge about the type of barriers to learning experienced the learner with cerebral palsy by means of the process of identification. Horsfall (2002) suggests the identification steps and they are:

- observation of the learner
- description of what the learner knows and can do and understand. The best is to start with positives for they enable the teacher to know the strengths and interests of the learner
- description of the learner's inabilities
- recording the difficulties of the learner because problems identified indicate which learning activities should be done
- reading of previous records of the learner

- inferring or guessing why the difficulties are occurring
- formulation of teaching plan if the learners needs extra assistance
- involving “support teaching, team teaching and co-operation between special needs teachers and class teachers... as well as involving classroom change” (Bayliss 2003).

### **3.7 Summary**

Chapter 3 has discussed the problems experienced by all concerned in the implementation of inclusive education. The chapter has shown that international events especially with regard to inclusive education have influenced South Africa to change its education system. It also looked at South African environment and factors which led to change in the education system. Advantages and limitations of inclusive education internationally and in South Africa have been identified.

With regard to learners with cerebral palsy, methods of including them in ordinary schools and methods of addressing barriers to learning of learners with cerebral palsy have been referred to.

In chapter 4 the focus will be on attitudes to inclusive education of learners with cerebral palsy, with special reference to attitudes of Xhosa parents.

## CHAPTER 4: ATTITUDES OF XHOSA PARENTS TOWARDS THEIR LEARNERS WITH CEREBRAL PALSY

### 4.1 Introduction

Chapter 3 focused on the inclusive education of learners with barriers to learning. It also indicated that learners with cerebral palsy and their educators encounter problems in inclusive educational settings. In chapter 4 attitudes to learners with barriers to learning, especially of parents will be discussed within local and international contexts.

Thompson (2004) has commented: "For as long as humans have existed, some percentage of people within the various populations have been characterized by disabilities. A disability is by nature, a deviation from what is considered to be normal". It may be assumed, therefore, that people without barriers are likely to react toward those with barriers. *Disability Awareness in Action* (2004) published a poem written by Estella Jossam about people's attitudes toward her. She wrote:

People don't see me	If I handle my crutches
They think I am useless	they move away quickly as though a
Say any word they want.	plane's taking off.
Don't I think as they do?	Don't do anything for me!
I need to be recognized!	I need to be on my own.
If I walk down the street	If I go for work
They say: "There's a	They say, "No - give her
cripple!"	this special, light job".
But 'special' means	And remember
discrimination.	my choice is not a mistake.
I need to express my rights	Let me be shy for myself.
to say what I want.	Let me speak for myself.

The poet explains that people with barriers are aware of other people's reactions towards them. In this regard, Enns (2004) supports the view of Estella. He states: "Historically, handicapped people have been badges of shame and objects of pity and embarrassment to families and communities... We see the disability, the white cane, crutches, hearing aid and wheelchair, but not the person".



In this chapter topics related to parental attitudes will be discussed. These include the historical development of attitudes towards people with barriers, universal parental attitudes and factors causing parents to react, family coping strategies, the effect of having a learner with a barrier on the family, socio/community reactions and their effects on learners with barriers to learning, traditional African attitudes to such learners, South African parental attitudes and their effects on learners with barriers to learning.

#### **4.2 Brief historical development of attitudes toward people with barriers – a framework for change**

Bfi Education (2004) is of the opinion that "having a clear understanding of where thinking about disability has come from is important in order to see that underlying negative attitudes and stereotypes have been reinforced by society and religion over many centuries".

Similarly, Pinpoint Online (2004) comments: "History plots landmark events and trends in the development of special needs issues and the movements of people with special needs from ancient times to the present day".

Shapiro (1999:145) regards knowledge of the history of attitudes toward people with barriers as essential because it:

- Gives insight into the origins of the existing attitudes.
- Provides a better understanding of attitudes.
- Reveals an evolutionary progression.
- Suggests how far society has come in accepting, treating and integrating people with barriers.
- Reminds how far we must still go.
- Teaches us some important comparative lessons.

Not all historical periods and accompanying attitudes will be discussed in this section. However, some examples are given which will serve to indicate the origin and development of attitudes during certain periods in the history of mankind. Moreover, in this section in this chapter children are referred to as learners. The rationale for the terminology is that infants learn from birth.

#### 4.2.1 Ancient times

According to Pinpoint Online (ibid), ancient times refer to the biblical, Greek and Roman periods.

##### 4.2.1.1 Biblical era

###### *a) Old Testament times*

Some books of the Old Testament contain a number of references to people with barriers. A few of these people were accepted by society while others were not. Moses in Exodus 4:10-17 (American Bible Society 1997:94) suffered from a speech impairment, yet he was socially accepted, became a leader and liberated the Israelites from Egyptian slavery.

Other Old Testament references expose some negative attitudes to people with barriers. Leviticus 21:16-24 and 22:1-6 list socially unaccepted people with barriers such as the blind, lame, the disfigured or deformed, cripples, hunchbacks, dwarfs, those with eye or skin diseases and eunuchs (castrated males). Reasons for naming them were that they were considered to suffer from a divine curse or from God's punishment for their fathers' or their own sins (American Bible Society 1997: 187-188, Preacher's Magazine Sermon 2005).

It may be concluded that during Old Testament times social attitudes to people with barriers were severe. The reason was that they bore religious and social stigmas by being different from other people in appearance.

###### *b) New Testament times*

During New Testament times people had similar attitudes to those held during Old Testament times. Even religious people like Jesus' apostles were not different from the rest of society. In John 9:2 they asked: "Teacher, whose sins caused him to be born blind? Was it his own or his parents' sins?" (American Bible Society 1997:1660).

Preacher's Magazine Sermon (2005) states that Jews divided society into groups of the righteous and sinners, clean and unclean, sacred and profane, children of light and of darkness, Jews and Gentiles. In contrast Jesus' attitudes to those with barriers were positive.

He healed those with barriers, communicated with prostitutes and ate with tax collectors (American Bible Society 1997:1453-1684). He was, among others, put to death for transgressing social beliefs towards people with barriers.

#### 4.2.1.2 Ancient Greece and Rome

During the fifth century before Christ (B.C.) Hippocrates' influence resulted in distinguishing medicine from superstition. Attempts were made to diagnose and treat physical and mental illnesses. The Greeks, however, were infatuated with the desire for physical perfection. The result was that the Athenians regarded the well shaped body as good and the body with barriers as bad (Bfi Education 2004, Rieser 2004). Most of the learners with barriers to learning were therefore put to death.

The attitudes of the Romans, during ancient times, loosely paralleled those of the ancient Greeks.

#### 4.2.2 The Middle Ages

During this time the belief in the supernatural was intense. Barriers were associated with witchcraft, superstition and congenital disorders. People with barriers were ridiculed and/or regarded as the manifestations of evil. They were persecuted and killed because it was thought that they brought disaster on society (Casey 2004; Shreve 2004; Bfi Education 2004).

#### 4.2.3 Pre-industrial period

During the era of primitive cultures, as Enns (2004) states, problems resulted from interactions between barriers and the environment. Survival depended on strength, agility and sensory acuity. This implies that physical barriers were hindrances. In such cultures intellectual superiority and the skill to read, calculate and artistic abilities were of little value, so the intellectually gifted learners with barriers "were left to die while the moderately retarded were allowed to survive because their barriers were less handicapping".

Shreve (2004) adds: "The nomads considered people with disabilities as useless because they could not contribute to the wealth of the tribe. This type of reasoning gave them permission to leave people with disabilities to die whenever the tribe moved on to a new location".

#### 4.2.4 The Renaissance

This is the period between Middle Ages and modern times. During this time people with barriers received medical care and treatment. For the first time people with barriers had access to education. They also participated in the activities of their communities (Shreve ibid).

However, Casey (2004) adds that communities institutionalized and segregated people with barriers. This was done when they were judged as incapable of fitting into certain social situations. Segregation of such people continued even after the completion of their education.

#### 4.2.5 19th century

During this century there was more segregation of people with barriers. They were socially rejected and were regarded as 'worthy poor' if they could work. They were given Poor Law Relief. This implies that they had a right to be accommodated in the workhouses or could receive money from public funds. People with barriers became more and more dependent on the medical profession for cures, treatments and benefits (Bfi Education 2004).

Bfi Education (ibid) goes on to state that the influence of Darwin's theory of evolution and natural selection also began to affect people with barriers. They were placed in single-sex institutions for life or sterilized. The belief of that time was that people with barriers would weaken the gene pool. Separate special schools and day-care centers were established. The International Congress in Milan in 1881 outlawed Sign Language so that the deaf people would be unable to increase in numbers (outbreed) and thus overwhelm the population of hearing people.

#### 4.2.6 20th century

Rights movements of people with barriers characterized this century. For example, First World War injured veterans campaigned for rights to work through the National League for the Blind and Disabled in the United Kingdom. In the United States of America activists with barriers campaigned against euthanasia and assisted suicide. Disability movements clamoured for the end of segregating people with barriers. Parents campaigned for human rights for their children with barriers (Bfi Education ibid).

Enns (2004) explains that this was the period when the medical model, therapy, programmes, sheltered workshops and specialized schools were prevalent. Segregation continued and attitudes toward people with barriers remained unchanged.

#### 4.2.7 The 21<sup>st</sup> century

According to Bfi Education (2004) people with barriers "still struggle for the right to use public transport, get into buildings, go to school or college with their friends, or get a job. Although civil rights legislation, such as the Americans with Disabilities Act (1990) or the Disability Discrimination Act (UK 1995) have helped, people with barriers still often feel that the dominant culture sees them as different from everyone else because of persisting stereotypes of disability".

Bfi Education (ibid) goes on to state that what people with barriers desire most is to be accepted for whom they are and to have their rights guaranteed in law and in practice.

The question is: If attitudes have been mostly negative throughout history, what kinds of attitudes prevail today? Section 4.3 intends to provide the answer by discussing parental attitudes to learners with barriers to learning, such as those with cerebral palsy.

### **4.3 Parental attitudes toward their learners with barriers to learning**

#### 4.3.1 Factors that cause parental reactions

Smith et al (2001:490) list some universal and general factors that cause parents to react negatively towards their learners with barriers to learning. Some of these are:

- Expensive medical treatment or hospitalization that may occur repeatedly and for extended periods.
- Heavy expenses for needs such as special food and equipment.
- Transportation problems.
- Time away from jobs to get the learners with barriers to learning to consultations and treatment.
- Lack of affordable childcare.
- Limited time to meet the needs of other family members.

- Limited opportunity for recreational or leisure activities.
- Difficulty of locating and additional expense for babysitters qualified to care for a learner with a barrier to learning.
- Babysitting needs for other learners at home.
- Lack of respite care facilities.
- Marital problems arising from finances, differences about management of the child's barriers to learning, or feelings of rejection by husband or wife that he or she is being passed over in favour of the learner. The researcher in this study is of the opinion that single (divorced, unmarried or widowed) mothers, particular, may also experience financial problems.
- Lack of understanding which may lead the parent to accuse the learner with a barrier of being lazy and not trying.
- Low expectations that limit the learner's success, for example, the barrier to learning.

Schoeman and Schoeman (2002) record specific factors which exist in "impoverished rural African contexts. Once they have overcome the widespread prejudices and suggestions of witchcraft which abound in many areas, parents are confronted by the wall of inaccessibility constructed by society and often even by professionals".

Thus, African parents, as argued by Schoeman and Schoeman (ibid), face problems caused by:

- Professionals who operate within a typically modernist (medical deficit) approach toward barriers to learning, even though it is totally inappropriate within an African context. However, the researcher does not agree with this statement because medical intervention will be always required for certain impairments such as cerebral palsy.
- Lack of empowerment which restrains parents from becoming partners in decisions concerning their learners' education. The opinion of the researcher is that many parents do not want to involve themselves in the child's education.
- The constant lack of facilities and resources experienced by rural Africans.
- The persistent idea among parents of learners with barriers to learning that they are so different or exceptional that they can never become part of the normal social and education context.
- In a specific rural area in South Africa, for example, there are only two government

employed speech therapists available to provide services in a region spanning hundreds of kilometers. They spend 80% of their time screening learners with hearing problems. In the end parents are left depressed and the needs of their children unanswered.

In some cases parents are also affected by other influences enumerated in the next paragraphs.

#### 4.3.1.1 Family size

Another factor is the family size. Recent research findings are that older mothers of learners with barriers to learning experience more stress than younger ones. They may have problems in meeting additional challenges of such learners especially if they are the youngest in their families (where there are more children) because these children require changes in their child rearing skills (Moore et al *ibid*). However, the researcher is of the opinion that siblings may assist the mother by taking care of the child with barriers to learning.

#### 4.3.1.2 Cultural influences on the family's view of barriers to learning

Sands et al (2000:82) are of the opinion that different cultures attach different meanings to barriers to learning. They state that culture influences the emotional and intellectual responses of parents. Culture may attribute the causes of barriers to learning as fate or the fault of the family or of the learner. Punishment for family sins may also be a cultural belief.

#### 4.3.1.3 Changing structure of a family

Attitudes within a family may be affected when its structure is changed. This implies that if there is a change in one member or feature of a family, there will be changes for other members and other aspects in that family. For example, a barrier to learning that affects one member is likely to affect other family members (Moore et al 2002:52).

#### **4.4 Effects of a learner with barriers to learning on parents**

##### **4.4.1 Broken marriage**

A barrier to learning in a learner can also affect the marriage of parents. Some reasons for the break up are that such a learner thwarts the family's future economic security. This implies that the affected learner will not be able to contribute financially toward the family's income. The father may also divorce his wife and marry another in the hope that the latter will give birth to healthy babies. The divorced mother is thus forced to become the only breadwinner in her family (Miles 2004).

In order to be able to face the problematic situation in families with learners with barriers to learning, families adopt certain coping skills/styles such as the ones stated below.

##### **4.4.2 Affected parental feelings, parental reactions and family coping strategies**

When biological parents do not take care of their affected learners, grandparents may act in *loco parentis* towards their grandchildren with barriers to learning. Their reactions to such grandchildren may or may not be similar to those of the biological parents. Their reactions are, therefore discussed together with those of parents.

###### **4.4.2.1 Main cause of reactions**

Smith (2006) describes some experiences of parents as follows: "The day my child was diagnosed as having a disability, I was devastated - and so confused that I recall little else about those first days other than heartbreak. Another parent described this event as a 'black sack' being pulled down over her head, blocking the ability to hear, see, and think in normal ways. Another parent described the trauma as 'having a knife stuck in her heart'".

Smith (ibid) goes on to state that these vivid descriptions do not sufficiently describe many emotions that flood parents' minds and hearts when they receive any bad news about their child.

The researcher is of the opinion that feelings of devastation, confusion and trauma (severe intellectual stress) are likely to cause parents to react towards a threatening object or situation. Parents and grandparents may use different coping skills to adjust themselves to the learner's



barrier to learning. Techniques used, according to Moore et al (2002) are:

- Seeking support from extended family members and friends.
- Accessing community support services.
- Participating in church activities and seeking spiritual guidance.
- Seeking counselling.
- Using individual cognitive coping skills.

In fact, coping strategies such as denial, avoidance and aggression may be negative, but they are a step towards a positive adaptation to stress (Moore et al *ibid*). Coping strategies are discussed as follows:

#### 4.4.2.2 Some parental coping strategies

##### 1. *Initial reactions*

###### a) Shock

According to Murphy and Della Corte (2005), "the impending birth of a child fills the entire family with anticipation and delight. The hopes and joys of the prospective parents and grandparents are cruelly dashed, however, when the eagerly awaited infant is born with problems. The most heart-rending task of all falls to the parents who must break the news to the grandparents that the child has been born with a disability. Both parents and grandparents experience similar feelings of consternation, shock and grief".

Murphy and Della Corte (*ibid*) go on to state that the grandparents' reaction is doubled because they suffer for the learner and for the parents who are deprived the normal joy of being parents. The grandparents worry further if the child suffers from cerebral palsy because they think that it will affect his or her future welfare.

Parents and grandparents when in a shock state often report that they feel confused, numb, disorganized, helpless and unable to comprehend what they have been told. The duration of shock may be a few hours or few days (Hornby 1995:37). Numbness is essential because it is a "physiological response, and is nature's way of protecting us from feeling unbearable pain. This short-lived stage gives us time to develop ways of coping" (Murphy & Della Corte *ibid*).

## b) Stress and stress related conditions

Hornby (1995:36) is of the opinion that "discovering that your child has special needs resulting from a serious illness, a disability or a psychological problem is a traumatic event for parents". Reader's Digest Association South Africa (1998:885) defines trauma as an emotional disturbing experience. According to Stress Busters (2005), stress resulting from trauma, grows and damages both health and performance because "excessive worry is a major element in the vicious cycle of tension: the physical sensation of stress-tense muscles, headaches, insomnia and so forth lead to catastrophic stress-building thoughts which in turn aggravate unpleasant physical feelings, and so up the tension cycle".

### i) Types of stress

There are two types of stress, eustress and distress. Eustress is positive and is in the form of extra energy. It is a momentum which boosts one's productivity (Stress Dynamics 2005). The examples are that of the sudden surge of energy of sports people for maximum performance and the energy used when meeting deadlines.

The second type is distress and is destructive because it may result in different illnesses in a person (FASAP 2005, Stress Dynamics ibid). It may also be assumed that distress may cause a parent to react towards his or her learner with barriers to learning

### ii) Some types of distress/negative stress in parents

There are two types of distress, acute and chronic. Acute means sharp or severe, its onset is fast and is a short-term condition ranging from a few minutes to a few weeks. Chronic distress lasts longer and causes emotional and physical problems. It results from continuous acute stress where stress reactions keep the body continuously on alert (Medical Editorial Board 2005). Distress causes the following conditions in parents of learners with barriers to learning, such as those with cerebral palsy:

- Burn-out

This term refers to physical or emotional exhaustion (Reader's Digest Association South Africa 1998: 113). Some of the activities that cause tiredness in parents while trying to meet the needs

of learners with barriers to learning are cooking, changing incontinence pads, spoon-feeding and lifting and carrying the learner. They are not only day-and-night demands but also hourly realities for many parents year-after-year. Smith et al (2001:490) add that continuous day-and-night demands on parents provide routine but difficult care giving tasks.

Signs of burn-out as stated by Neils (2005) and Campbell (2005) are: chronic fatigue/exhaustion and a sense of being run down, anger at those making demands, self-criticism for putting up with the demands, cynicism (a sneering fault-finder), negativity and irritability, a sense of being besieged, exploding easily at seemingly inconsequential things, suspiciousness, increased degrees of risk taking and trembling when holding an object.

- Aloneness and parents' exclusion by friends/community

Exclusion refers to shutting or keeping out a person or thing from others (Reader's Digest Association South Africa 1998:276). Due to exhaustion and caring for the needs of a learner with barriers to learning the parent may be unable to go out. Aloneness leads to internal conflict because the parent may feel that he or she is alone in her predicament. The parent may try to ease the situation by establishing intimacy with their learner. If the learner with barriers to learning is the only child in the family and affects intimacy, the parent may be forced to bear with her aloneness (Hornby 1995:42).

Families with a learner with barriers to learning may experience a restricted social life, for example, they may be unable to visit friends. They may be unable to use community facilities such as public transportation. Restrictions are especially experienced when the learner is very young, has behaviour problems or when barriers are severe (Hornby 1995:57-58).

- Inadequacy

This term refers to the inability to deal with a problematic situation (Reader's Digest Association South Africa 1998:408). Helplessness and feelings of low-esteem may cause feelings of inadequacy in a parent.

Hornby (1995:42) states, "Most people strive to find some meaning in life, typically through fulfilling satisfying social roles such as husband and wife. When they are frustrated in achieving a rewarding parental role, perhaps because the child has a communications problem, parents

may find it difficult to achieve meaning in their lives and therefore become vulnerable to feelings of insignificance".

- Present and past orientation

Most people look forward to and anticipate their learner's future with enthusiasm. Parents of learners with barriers to learning tend to view the future with apprehension (fear). This implies that most people are future oriented, but parents of learners with barriers to learning may focus on the present or past (Hornby *ibid*). Such a state of affairs is likely to disillusion parents. They may also neglect to train the child to become an independent future adult.

- Loss of symbolic immortality

Most parents wish to have healthy learners. Such a learner assures parents that their name will continue to exist in future generations. This is what is called symbolic immortality of parents. A learner with barriers to learning may be a threat to parents' symbolic immortality. This may be the case where such a learner is the only child of his or her parents (Hornby *ibid*). It may be deduced, therefore, that loss of symbolic immortality may cause parents to react by not accepting nor educating the child.

- Anxiety

Reader's Digest Association South (1998:45) describes anxiety as a state of being uneasy in the mind. There is a difference between fear and anxiety. With regard to fear, the person knows and is scared of what is threatening him or her. Anxiety, on the other hand, refers to a feeling where a person is not aware of what is threatening him or her. Anxiety is likely to affect the functioning of a parent because in such a state the parent feels threatened, uneasy and helpless. Needs of a learner with barriers to learning may not be met by such a parent.

Murphy and Della Corte (2004) are of the opinion that anxiety and depression can be reduced when a parent is actively involved in the learner's welfare.

- Grief and depression

Grief is a response to loss, the loss of a healthy learner whom parents eagerly looked forward to

during pregnancy. This means that parents experience feelings of sadness. Depression, on the other hand, is a pathological state of extreme melancholy/sadness (Reader's Digest Association South Africa 1998:219).

Some signs of depression in a parent are:

- *Sleep*: sleeping patterns change, the person develops insomnia or the inability to sleep or does not experience restful sleep (Campbell 2005). According to Smith et al (2001:492), sleeplessness reveals that the parent is confused, unable to make decisions and has a mental overload. Confusion is a result of not understanding what is happening and what will happen.
- *Interest*: is a concern, curiosity or holding of attention (Reader's Digest Association South Africa 1998:422). Loss of interest is an inability to find pleasure in activities that a person has previously enjoyed. The person may start neglecting his or her hygiene (Campbell *ibid*). This may be a case where the parent has lost interest in a child with barriers to learning.
- *Concentration*: is affected by on-going problems with a diminishing ability to focus attention on tasks and activities. These are combined with "paralyzing indecision" (Campbell *ibid*).
- *Appetite*: the weight of a person may change; he or she may become thin or obese (Campbell *ibid*).

Murphy and Della Corte (2005) are of the opinion that grief, depression and anxiety are some of the reactions that occur and re-occur. They advise that the best way to deal with depression is to accept its existence or to seek professional assistance if it is generalized, pervasive and extreme.

## 2. *Secondary reactions*

### a) Anger and misplaced anger

Anger may be defined as a way of assigning blame to others. The researcher in this study is of the opinion that reasons why people become angry can be classified into two categories:

External reasons: situations outside one over which one has little or no control, except how one

reacts to them.

Internal reasons: are linked to how a person thinks and feels. They are the combination of feelings about the situations around the person and stress or accumulated stress.

Examples of inner and outside reasons are described by Hornby (1995:38) and Smith et al (2001:16; 492) as follows. Anger in parents and grandparents arises when they realize that the learner's condition, instead of disappearing, is becoming more apparent. Their misplaced anger may be directed toward doctors, therapists, husband, wife or the learner with barriers to learning. Causes of anger may also lie in feeling of guilt.

Hornby (ibid) and Smith et al (ibid) go on to state that there is no easy method of reducing anger. However, expressing anger enables parents and grandparents to move forward to the stage of accepting the learner and his or her condition.

Murphy and Della Corte (2004) state that "anger in its extreme form can manifest itself as uncontrollable rage, thus paralyzing and frightening at the same time". This implies that family members, relatives and neighbours who are scared by manifestations of anger may be unable to assist such a parent.

#### b) Denial and guilt

Murphy and Della Corte (2004) describe denial as a feeling of unreality, whereby one denies the fact of the barrier to learning. Grandparents who live far away and lack firsthand experience may deny the reality, hoping that the grandchild will outgrow the defect. Grandparents may even avoid phoning or visiting. They may be unaware that this avoidance is increasing the sorrow of the parents of the learner. This behaviour robs parents of the support they need. Guilt serves no purpose. It only shuts out the world and closes off avenues of help.

Gascoigne (1995:14) states that parents experience denial in the first few weeks and months after diagnosis or realization of the learners' problem. The parent who remains in denial will never come to terms with his or her learner's difficulties, and so will not be able to help the learner to progress in life.

Gascoigne (ibid) explains that parents feel responsible for their learners, so the parents take whatever happens to the learner very personally. The parent "bears the responsibility, the parent takes the blame. This propensity to shoulder blame, leads to the most damaging emotion of all - guilt". Guilt feelings resurrect whenever a parent meets a teacher at school.

### 3. *Tertiary reactions*

#### a) Detachment

According to Hornby (1995:39) detachment refers to a stage where parents "feel empty and nothing seems to matter. Life goes on from day to day but it has lost its meaning". It is also a stage where parents gradually begin to accept that they have lost a healthy learner. This stage is also the beginning of the adaptation process.

#### b) Re-organization

At this stage the parents begin to pay attention to what their learner can do. Parents gain interest in participating in parent education programmes. They may also join support groups. Parental participation in such programmes and meetings of parents facing similar conditions cause parents to "feel better about the whole situation and is [are] useful in helping parents to make progress towards adaptation" (Hornby ibid).

#### c) Acceptance

Lerner et al (1998:49) describe acceptance thus: Acceptance "means that the parent can look past the disability, and accepts the child as the child is... the parents can envisage a life for themselves and their child, in spite of the disability". It is the re-organization that paves way for the acceptance of the affected children. Parents start realizing that their learner has needs to be met and that the learner is a valuable member of the family (Smith et al 2001:49). Parents, while progressing from shock towards acceptance, may experience the following:

## **4.5 Mixed attitudes**

### **4.5.1 Alternating feelings in a parent**

An attitude varies; it can be positive and then change to negative. This can be illustrated by a change in feelings, such as, from acceptance to rejection. This implies that a parent may accept the learner with barriers to learning and the next minute reject the child. This indicates that acceptance of the learner with barriers to learning does not necessarily eliminate negative feelings in a parent.

Mixed feelings are essential because they pave way for the parental adaptation process to the existing situation. According to Hornby (1995:39), the adaptation process is not as clear cut as simply moving from stage to stage would suggest. One reaction may be uppermost at a particular time but certain other reactions involved in the process will also be present.

### **4.5.2 Simultaneously occurring feelings**

Hornby (ibid) goes on to explain that when a person's main reaction is one of anger, he or she will also experience a fair amount of denial and sadness at the same time and lesser amounts of the other reactions will also be present. Sadness and grief are considered to be overriding feelings experienced and are the ones, which, more than any others, pervade all stages of the adaptation process.

## **4.6 Universal attitudes**

Parents are likely not only to react to learners with barriers to learning but also to their inclusive education. In order to illustrate this, attitudes of parents to this type of education in three countries have been selected for discussion. These are: the United States of America, United Kingdom and South Africa. The first mentioned countries serve to provide international examples while the case of South Africa represents local parental attitudes to inclusive education.

### **4.6.1 United States of America**

The National Information Center for Children and Youth with Disabilities (NICHCY) explains why the role played by parents is important in the education of the learners with barriers to



learning in the United States of America. They are:

- 1) Equal partners in the team that develops their learner's IEP (Individualized Educational Programme) and
- 2) They care deeply that the learners learn and grow as people.

Research findings of Palmer et al (2001:467) reveal that parents of learners with barriers to learning are of two types: those who favour inclusion and those against it. Those who support inclusion believe that their learners will learn better because of higher expectations, a stimulating environment and the presence of non-affected learners.

Other advantages voiced by parents are that such learners will be better accepted in the community, have a chance to participate in a wide range of activities, be prepared to function in the real world, develop sensitivity to others, understand differences in people, and become more aware of their own strengths and weaknesses (Rafferty et al 2001:280).

Some parents gave reasons for not favouring inclusion. These are the severity of barriers to learning of the affected learners; inclusive schools will not provide sufficient special assistance or individual instruction, teachers might not be adequately qualified to address the needs of learners with barriers to learning and special related services that their learners may require are lacking (Rafferty et al *ibid*; Palmer et al 2001 *ibid*).

It may be assumed that attitudes of Americans may be similar to those of British parents.

#### 4.6.2 United Kingdom

In this country some parents favoured special schools and were against their closure. Cook and Swain (2001:191) report how parents reacted. They "fought to save the special school... taking their case to court". The reason was that they considered special schools to be good for they met the needs of their learners with barriers to learning. Parents feared the placement of their learners in the mainstream schools because of:

- The larger size of the mainstream as compared to the small special school and the staff/learner ratios in class.
- Lack of supervision and the safety of learners with barriers to learning during break

times.

- Their learners would face a busy and complex setting.
- The staff's lack of training and experience in teaching and in meeting the complex educational, social and emotional needs of their learners.
- Resources allocated to their learners would be reduced.
- Access to medical facilities would be reduced.
- Their learners would be teased and bullied.
- Non-affected learners would not accept their learners with barriers to learning.
- Identified inclusive schools were not their local mainstream schools.

In the light of the above discussion, certain parents in South Africa may favour inclusion. The question is: If parents in the above-mentioned countries demonstrate both positive and negative attitudes, what are those of South African parents?

#### **4.7 The situation in South Africa**

##### **4.7.1 General parental attitudes towards the learners with barriers to learning**

There is an acute shortage of literature that deals generally with parental attitudes towards learners with barriers to learning in South Africa. With regard to Xhosa parents' attitudes no literature could be located in South African libraries; hence the researcher resorted to research conducted in neighbouring countries such as Botswana. It is possible that black parents in Botswana may have similar customs and attitudes as black parents in South Africa.

In order to comprehend the situation of Xhosa parents in South Africa it is essential to discuss traditional African attitudes to learners with barriers to learning. Grol (2004) suggests why insight into such attitudes is necessary:

- It explains motives as to why people behave in a certain way toward learners generally and towards learners with barriers to learning specifically.
- It sheds light on how people feel in the presence of learners with barriers to learning.
- It shows how people explain barriers to learning.

It is, therefore, necessary to discuss the position of the learner in traditional African society,

traditional African attitudes toward learners with barriers to learning and African socio-economic views.

#### 4.7.2 The position of a learner in a traditional African society

Grol (ibid) continues to explain that in traditional African society the child is a highly valued member. The reasons are:

- The learner assures the biological continuation of the family.
- The learner contributes to the economy and social prosperity of the community.
- The existence of the learner implies, above all, the spiritual existence of society.

It may be deduced that the black parents in South Africa, especially the Xhosa, attach the same values to learners with barriers to learning as do those in Botswana. A Xhosa learner with a barrier to learning in the Eastern Cape Province may be regarded as:

- A threat to the biological continuation in a family.
- Not being able to contribute economically to family and social prosperity.
- A danger to the spiritual existence of the community. Africans believe that learners with barriers to learning are responsible for bringing the wrath of God and the ancestors. Therefore, disasters such as drought, illness and death are attributed to these learners.

In Africa and possibly in South Africa the learner with barriers is cared for within the extended family since education is not only the responsibility of one family. It involves grandfathers, grandmothers, father, mother, uncles, aunts, brothers, sisters, cousins, nephews and nieces. "Nevertheless, a majority of children with a disability are not enrolled in formal education. Traditional attitudes and socio-economic views might explain this absence" (Grol 2004).

#### 4.7.3 Traditional attitudes towards learners with barriers to learning

Research findings of Hops (in Grol ibid) in Botswana on attitudes towards learners with barriers to learning were the following:

1. *Situation:* People reacted when meeting a learner with barriers to learning.

2. *Beliefs*: People believed that barriers in a learner were caused by witchcraft or by parents who violate traditional standards and/or values.
3. *Feelings and behaviours*: Such learner were feared and pitied. People reacted by isolating and neglecting them.
4. *Consequences*:
  - Learners with barriers were hidden away in remote villages. Hidden learners did not attend formal education and hence did not develop.
  - Barriers and attitudes to barriers gave rise to a lack of various abilities in such learners.

It may be assumed that South African parents in general and particularly Xhosa parents are likely to entertain and practise such traditional feelings and behaviours.

#### 4.7.4 Socio-economic views

Grol (ibid) further refers to the research of Obani in 1997 in Botswana, which shows the relationship between the barrier and the economy in that country. In Botswana anyone with barriers is regarded as having socio-economic barriers and is viewed as unintelligent. They are regarded as lacking productive capacity. It is, therefore, generally believed that the employment of such people is detrimental to productivity in Botswana.

### **4.8 Specific South African parents' reactions towards their learners with barriers to learning**

#### 4.8.1 Disunity between father and mother of learner with barriers to learning

Attitudes of parents of learners with barriers to learning in this country may not be different from those of parents in Botswana. Lansdown (2004) confirms this opinion by stating that in South Africa, especially in rural areas: "it is commonplace for men to leave their wives after the birth of a disabled child... [in: TMS] ill urban areas where men also frequently leave their wives after a disabled child is born, it seems that men are seeking to escape the associated pressures of caring for the child". Thus, in South Africa the learner with barriers to learning may disrupt and cause the break-up of marriages.

Lansdown (ibid) concludes by stating that South African parental reactions impact negatively on their children: "The impact of these negative attitudes is that disabled children are frequently

hidden from view, kept in back rooms. Their existence and their human rights largely denied”.

The attitudes of South African parents may not only affect learners with barriers to learning at home but also their inclusive education at school.

#### 4.8.2 South African parental reactions to the inclusion of their learners with barriers to learning

South African policies on inclusive education have been discussed in 3.4.2. It is, however, essential to refer to the legal rights of learner with barriers to learning and their parents' reactions to inclusion.

##### 4.8.2.1 Brief historical background

Lansdown (2004) reports that in 1994 the President of South Africa pledged a commitment to place learners first, thus abiding by the United Nations resolutions and international laws which recognized learning barriers as a "ground for protection against discrimination (Article 2) and to promote the fullest possible social integration of disabled children (Article 23)". The Bill of Rights in the 1996 Constitution guarantees fundamental rights to all citizens. It contains an equality clause and the right to freedom from discrimination. This Bill of Rights also guarantees that the interests of the child are of paramount importance in all matters concerning the child. The Promotion of Equality and Prevention of Unfair Discrimination Act of 1999 translates the principle of equality into law. This Act emphasizes that learners have the right to education and supports their education.

Lansdown (ibid) concludes by stating that the rights ensure equal treatment of learners and people with barriers and gives them the same rights enjoyed by non-affected South African citizens.

Since 1995 parents have been involved in the inclusive education of their learners. They have been, for example, part of the National Education Task Team. The South African Federal Council on Disability set up this team in October 1995. Parents work in partnership with barriers to learning organizations. Together they host public meetings and workshops on inclusion. The South African Schools Act of 1996, Section 5(6) enforces their participation (Belknap et al 1999:172-173).

However, as Belknap et al (ibid) state, "There is still a large majority of parents who have never heard of the term 'inclusive education' and/or have little or no idea of what it entails. Of those who have been exposed to the debate around inclusion, integration or mainstreaming, opinions remain sharply divided, as they are worldwide".

Belknap et al ibid further mention some reactions of parents in disadvantaged areas especially where there are no special schools. These include, among others, the following:

#### 4.8.2.2 Reactions of parents in disadvantaged areas in South Africa

The parents of learners with barriers to learning, as Belknap et al (ibid) record:

- Are suspicious of the motives of those who argue that special schools are not necessarily the best option.
- They feel that facilities denied to them in the past will still not be available to them and their learners.
- Parents who received information about inclusive education are becoming more receptive to the idea of inclusive education.
- Some parents are apathetic (have few feelings) towards their learners with barriers to learning. This implies that they refuse to be involved in the inclusive education of their learners with barriers to learning.

Apathy originates from the past educational situation where school authorities had an attitude of "give us your child to educate, let us do it as we see fit, and don't interfere" (Belknap et al ibid).

## 4.9 Synthesis

Chapter 4 has examined the reaction of parents toward learners with barriers to learning. Findings were that throughout history parents have reacted in some way to children with barriers. Moreover, different parents react differently to learners with barriers to learning and that there is no fixed pattern of how parents move from one stage to another. Some factors fuelling parental attitudes are the socio-economic conditions, family size, cultural influences on the family, changing structure of the family and broken marriages.

The chapter also revealed how researchers have described how parents progress from one stage to another before adapting to and accepting the learner with barriers to learning. These

phases include shock, denial, misplaced anger, grief and depression, detachment, re-organization and eventually acceptance.

Parents in other countries seem to react in the same manner as those in South Africa. Nowadays some parents seem to react positively to the inclusive education of their learner with barriers to learning by acknowledging and accepting it. Some do not know what inclusive education is and, therefore, are not willing to place their learners with barriers in inclusive schools.

It may be assumed, therefore, that there is a strong relationship between two variables, that is, barriers to learning and parental attitudes.

In chapter 5 research methodology will be discussed.

## **CHAPTER 5: RESEARCH DESIGN AND METHODOLOGY**

### **5.1 Introduction**

The focus of this chapter is the purpose of the research, research method, research design, data collection and data interpretation.

### **5.2 Purpose of the research**

The main aim of the research is to determine whether Xhosa parents with children with cerebral palsy require parent guidance programmes to assist them coping with their learners and to provide specific guidelines for the design of such programmes where needed. The literature study contained in chapters two, three and four provided the theoretical framework for the problem as well as the background for the design of the empirical investigation.

#### **5.2.1 Research problem**

The research problem has been formulated as follows (1.7.2):

Do Xhosa parents of learners with cerebral palsy need guidance programmes? If such programmes are needed, what guidelines can be given pertaining to such programmes?

Specific aims were developed to guide the research (1.8.2).

#### **5.2.2 Specific aims**

Apart from the literature study which familiarized the researcher with the topic and laid the basis for the empirical study, other aims included:

- To conduct empirical research among Xhosa parents with children with cerebral palsy.
- To provide specific guidelines for parent guidance programmes to meet the needs of these parents.

### **5.3 Research design**

The term research design refers to “constructed plans and strategies developed to seek, explore and discover answers to quantitative and qualitative research questions” (Taylor 2003:165). The research method chosen for this study involves a quantitative research



design whereby data was gathered from a large number of parents by means of a survey. The survey technique involves the collection of data about subjects through the use of a questionnaire. It is a popular and useful technique of data gathering since many different types of information can be collected.

#### 5.3.1 Selection of sample

A sample is defined as “a small-scale representation – a kind of miniature model – of the population from which it was selected ... But in many respects it will resemble it closely, and it is this resemblance that makes sampling so useful in the study of populations too large to survey in their entirety” (Searle 2000:64).

The target group for this study was comprised of Xhosa parents with children with cerebral palsy living in the former Transkei, which now forms part of the Eastern Cape Province. The Ikhwezi Lokusa Special School is attended by 180 Xhosa learners with cerebral palsy (1.3). Their parents or primary caregivers were purposefully selected for the sample. The questionnaire will be mailed to each of the 180 households.

#### 5.3.2 Data collection

Data was collected through the use of a questionnaire. The questionnaire may be defined as a “paper-and-pencil set of structured and focused questions” (Salkind 2003:140). The limitations of a questionnaire as identified by Salkind (ibid), Walliman (2001:236-237), Nardi (2003:59) and Neuman (200:261) can influence the data negatively. These limitations are listed below:

- They can suggest ideas that the respondent would not otherwise have entertained.
- Respondents with no real opinion or knowledge can answer the questions regardless.
- Respondents may be frustrated if their desired answer is not a choice.
- It is confusing if too many response choices are offered.
- Misinterpretation of a question can go unnoticed.
- Distinctions between respondent answers may be blurred.
- Clerical mistakes or marking the wrong response is possible.
- They force respondents to make simplistic responses to complex issues.
- They force people to make choices they would not make in the real world.
- The rate of responses is difficult to predict or control, especially if there is no system of follow-up.

In this study, a further limitation not mentioned above was that some parents might be illiterate. In such an event, the researcher opted to administer the questionnaire orally. However, in spite of these limitations, questionnaires are effective where the following requirements are met (Salkind ibid).

- The questionnaire does not make unreasonable demands upon the respondent.
- The questionnaire does not have a hidden purpose.
- The questionnaire requests information that respondents have.
- The questionnaire contains questions that can be answered.
- The questionnaire contains questions that are straightforward.
- The items and the questionnaire are in an attractive professional and easy-to-understand format.
- All questions and pages are clearly numbered.
- The questionnaire contains clear and explicit directions as to how it should be completed and how and when it should be returned.
- The questions are objective.
- Examples are given when necessary.

In this study the researcher endeavoured to meet all the above requirements.

### 5.3.3 The questionnaire and cover letter

A cover letter (which was translated into Xhosa) (see Appendix A) and a stamped addressed envelope for returning the responses accompanied the questionnaire. The questionnaire consisted of twenty closed questions. Parents were requested to mark their response with an X in the appropriate box. A copy of the questionnaire is contained in Appendix B. The original questionnaire was in Xhosa and a translated English version is provided for the reader. Although the parents completed the questionnaire anonymously, the return envelopes were numbered according to a corresponding list with the parents' details to keep track of who had returned the questionnaires. It was decided that parents who did not return the questionnaires would be approached and assistance such as oral completion would be offered if required. (Some parents might perhaps not be able to read.) Parents would, however, not be forced to complete the questionnaire in any manner whatsoever.

The permission of the principal of Ikhwezi Lokusa Special School was obtained prior to the distribution of the questionnaires. The files of learners with cerebral palsy were consulted for names and addresses of the parents with the permission of the social worker.

#### 5.3.4 Data interpretation

The data was statistically analyzed using Microsoft's Excel spread sheets and the findings were presented in pie charts in chapter six. Interpretation and discussion followed the captured data.

### **5.4 Conclusion**

In this chapter, the researcher discussed the research design to validate the scientific basis of the empirical investigation. In the next chapter the results of the empirical study will be discussed.

## **CHAPTER 6: RESULTS OF THE EMPIRICAL STUDY**

### **6.1 Introduction**

The results of the questionnaires, both those mailed and from the oral completion with parents who were not able to read or respond in writing to the questionnaire, are presented and discussed in this chapter. The results of each question is presented in a table, illustrated by a pie chart and thereafter interpreted. The interpretations are supplemented by the researcher's own indigenous knowledge of Xhosa culture (1.3).

### **6.2 The sample size and response rate**

One hundred and eighty questionnaires were mailed and 102 questionnaires were returned by mail. Another 54 questionnaires were completed during interviews with the respondents. These were mainly held when parents returned their children to school. The sample size thus equals 156.

### **6.3 Collected and interpreted results of the questionnaires**

In this section the questions as they occurred in the questionnaire are presented and the results indicated and discussed.

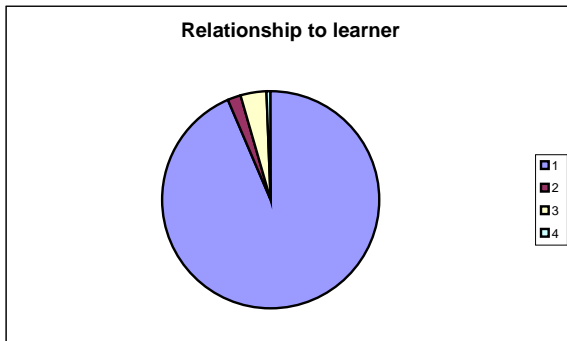
*Question 1: Are you a Xhosa parent?*

All the respondents (N = 156) indicated that they belonged to the Xhosa ethnic group.

Question 2: What is your relationship with the learner with barriers? Mother / Father / Guardian

**Table 6.1** Relationship to learner

Relationship to the learner	Number of respondents
1. Mother	146
2. Father	3
3. Guardian	6
4. Question not answered	1
<b>Total</b>	<b>156</b>



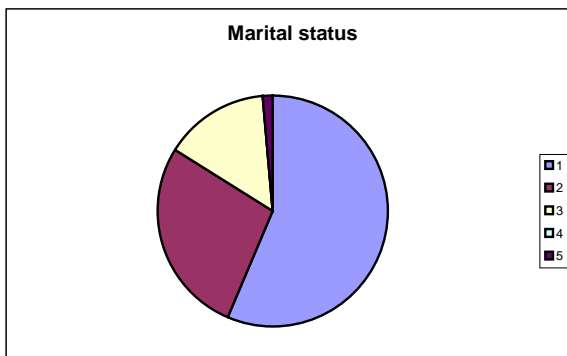
**Figure 6.1** Relationship to learner

The respondents consisted mainly of Xhosa mothers. This reflects the African context where mothers are the primary caregivers.

Question 3: What is your marital status? Married / Divorced / Widowed

**Table 6.2** Marital status

Marital status	Number and percentage of respondents
1. Married	88 (56%)
2. Divorced	43 (28%)
3. Widowed	23 (15%)
4. Single parent	0
5. Question not answered	2 (1%)
<b>Total</b>	<b>156</b>



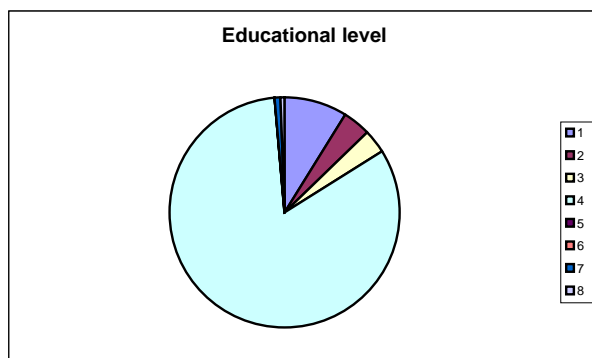
**Figure 6.2** Marital status

More than half of the respondents were married.

Question 4: What is your educational level? No schooling / Sub A / Sub B / Primary school / High school / Matric / Post matric qualifications

**Table 6.3** Educational level

Level of education	Number and percentage of respondents
1. No schooling	14 (9%)
2. Sub A	6 (4%)
3. Sub B	5 (3%)
4. Primary school	129 (83%)
5. High school	0
6. Matric	0
7. Post matric qualifications	1 (0,5%)
8. Question not answered	1 (0.5%)
<b>Total</b>	<b>156</b>



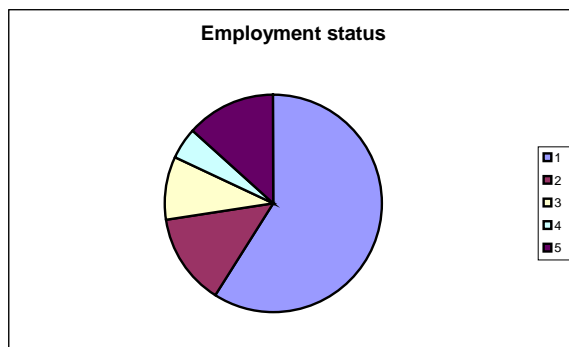
**Figure 6.3** Educational level

In general the respondents were not well educated; 83% of the respondents only have primary school education. This implies that parent guidance programmes should take their low level of formal education into account. This finding is also corroborated by the findings of the Report of the Truth and Reconciliation Commission (2005) pertaining to the level of education in the Eastern Cape.

Question 5: What is your employment status? Unemployed / Retired / Employed / Self-employed

**Table 6.4** Employment status

Employment status	Number and percentage of respondents
1. Unemployed	92 (59%)
2. Retired	21 (13%)
3. Employed	15 (10%)
4. Self-employed	7 (5%)
5. Question not answered	21 (13%)
<b>Total</b>	<b>156</b>



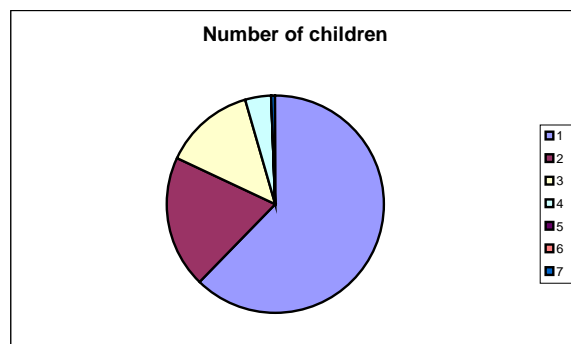
**Figure 6.4** Employment status

An alarming percentage – more than half of the respondents – are unemployed. However, since mostly mothers completed the questionnaires, the possibility remains that there may have been other breadwinners in the household. On the other hand, this finding is confirmed by Rhodes University (2006) which reported very high levels of unemployment in the Eastern Cape. One can also argue that the general low level of education (Question 4 above) contributes to unemployment.

Question 6: How many children do you have in the family? One to two / Three to four / Five to six / Seven to eight / Nine to ten / More than ten

**Table 6.5** Number of children

Number of children	Number and percentage of respondents
1. One to two	97 (62%)
2. Three to four	31 (20%)
3. Five to six	21 (13%)
4. Seven to eight	6 (4%)
5. Nine to ten	0
6. More than ten	0
7. Question not answered	1 (1%)
<b>Total</b>	<b>156</b>



**Figure 6.5** Number of children

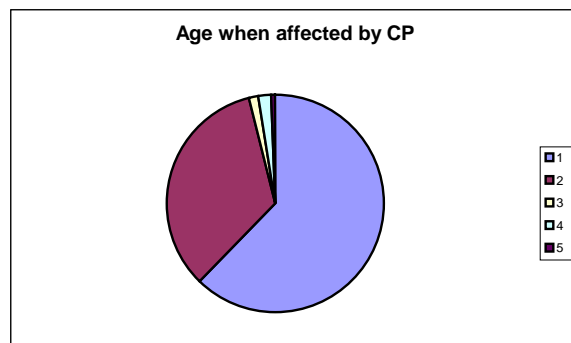
Most respondents – nearly two thirds – have one to two children. This indicates fewer children than is normally found in rural Xhosa families. The number is generally much higher since children are considered as economic assets and many children enhance the family status. It seems as if the birth of a child with cerebral palsy discourages parents from having more children (see 2.9.1.1)



Question 7: To the best of your knowledge approximately when did cerebral palsy affect your child? Born with it – one year / Two to three years / Four to five years / Six years and older

**Table 6.6** Age of child

Age when affected by CP	Number and percentage of respondents
1. Born with it – one year	97 (62%)
2. Two to three years	53 (34%)
3. Four to five years	2 (1%)
4. Six years and older	3 (2%)
5. Question not answered	1 (1%)
<b>Total</b>	<b>156</b>



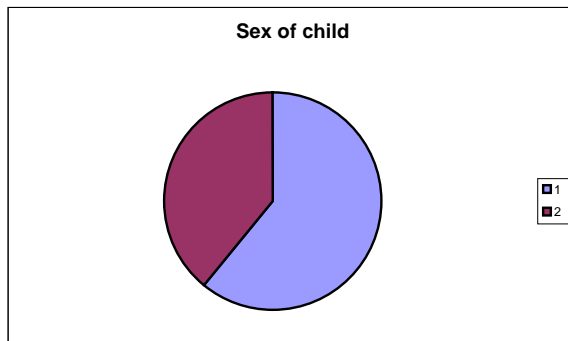
**Figure 6.6** Age of child

Nearly two thirds of the Xhosa children were either born with cerebral palsy or it became apparent during their first year. Nearly all the respondents (96%) were confronted with fact of their child's cerebral palsy by the time the child turned three.

Question 8: What is the sex of your child? Male / female

**Table 6.7** Sex of child

Sex of the child	Number and percentage of respondents
1. Male	95 (61%)
2. Female	61 (39%)
<b>Total</b>	<b>156</b>



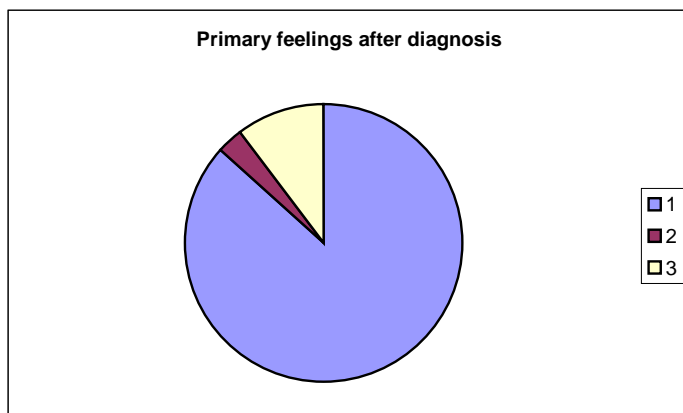
**Figure 6.7** Sex of child

More boys than girls are affected by cerebral palsy. Approximately two-thirds of boys are affected. If taken into account that boys are more valued than girls in the Xhosa culture, the blow to the parents is doubled.

Question 9: Shortly after your child was diagnosed with cerebral palsy, what was your primary feeling? Hurt / Chronic sorrow / Acceptance

**Table 6.8** Primary feelings after diagnosis

Primary feelings after diagnosis	Number and percentage of respondents
1. Hurt	135 (87%)
2. Chronic sorrow	5 (3%)
3. Acceptance	16 (10%)
<b>Total</b>	<b>156</b>



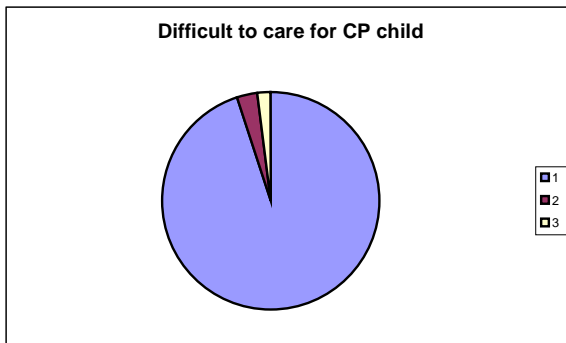
**Figure 6.8** Primary feelings after diagnosis

It is clear that most respondents experienced hurt after hearing the diagnosis.

Question 10: Do you agree with the following statement? It is difficult to care for your child with cerebral palsy? Yes / No

**Table 6.9** Experience of caring for child

Taking care is difficult	Number and percentage of respondents
1. Yes	148 (95%)
2. No	5 (3%)
3. Question not answered	3 (2%)
<b>Total</b>	<b>156</b>



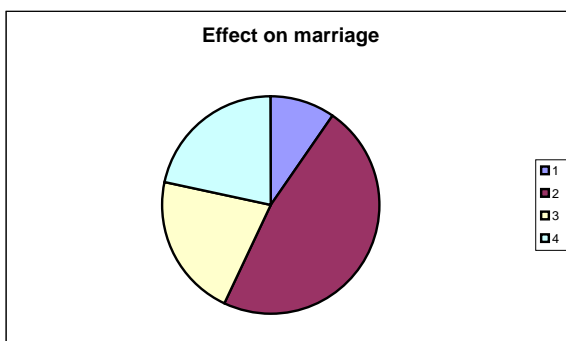
**Figure 6.9** Experience of caring for child

The predominant response is that it is difficult to take care of the child with cerebral palsy.

Question 11: Is or was your marriage or relationship with your companion affected by the child's cerebral palsy? Yes / No / No longer affected

**Table 6.10** Effect on marriage

Effect on marriage	Number and percentage of respondents
1. Yes	15 (10%)
2. No	74 (47%)
3. No longer affected	33 (21%)
4. Question not answered	34 (22%)
<b>Total</b>	<b>156</b>



**Figure 6.10** Effect on marriage

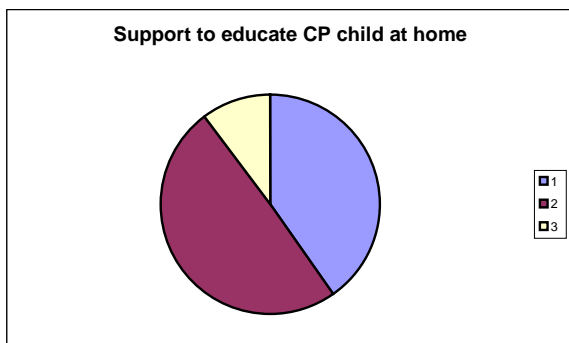
Nearly half of the respondents' marriages or relationships with their partners were not affected. This might suggest that tribal customs provide some support in as much that couples are expected to deal with all

sorts of difficulties in their relationships. However, nearly one third of the marriages or relationships is or has been affected despite the impact of local customs.

Question 12: How much support did you get from family members to educate the child with cerebral palsy at home? Much support / Average support / Little or no support

**Table 6.11** Support from family members

Support to educate CP child at home	Number and percentage of respondents
1. Much support	63 (40%)
2. Average support	77 (50%)
3. Little or no support	16 (10%)
<b>Total</b>	<b>156</b>



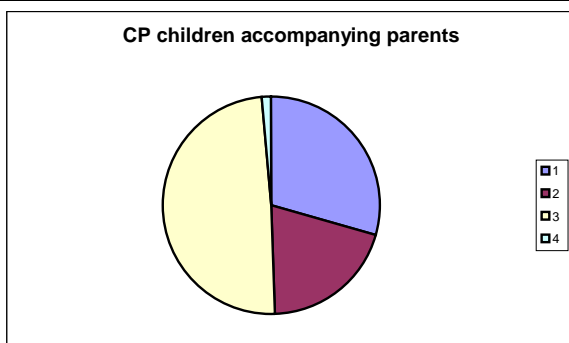
**Figure 6.11** Support from family members

In general, the respondents received strong to average support from their family members in the education of their child at home. In an African rural context women in the family are supposed to render assistance. However, from a cultural viewpoint males are not expected to render much assistance.

Question 13: Do your child with cerebral palsy accompany you on outings? Most of the times / Sometimes / Seldom or never

**Table 6.12** Accompaniment on outings

Parental outings with CP child	Number and percentage of respondents
1. Most of the times	46 (30%)
2. Sometimes	31 (20%)
3. Seldom or never	77 (49%)
4. Question not answered	2 (1%)
<b>Total</b>	<b>156</b>



**Figure 6.12** Accompaniment on outings

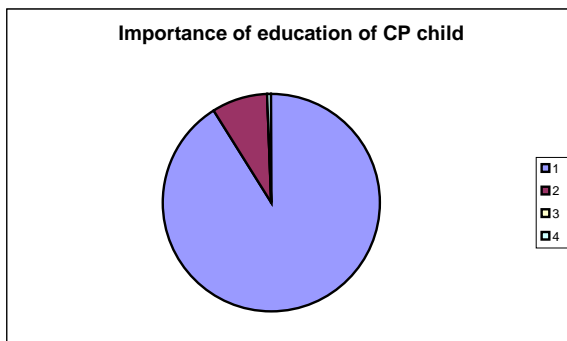
Nearly half of the children with cerebral palsy seldom or never accompany their parents on outings. They seem to be fairly isolated from the outside world of which their parents or caregivers are part. According to Grol (2004), this phenomenon is not unusual among African parents of

learners with barriers to learning.

Question 14: Do you think it is important to educate your child? Yes / To a certain extent / No

**Table 6.13** Importance of education

Importance of education of CP child	Number and percentage of respondents
1. Yes	142 (91%)
2. To a certain extent	13 (8%)
3. No	0
4. Question not answered	1 (1%)
<b>Total</b>	<b>156</b>



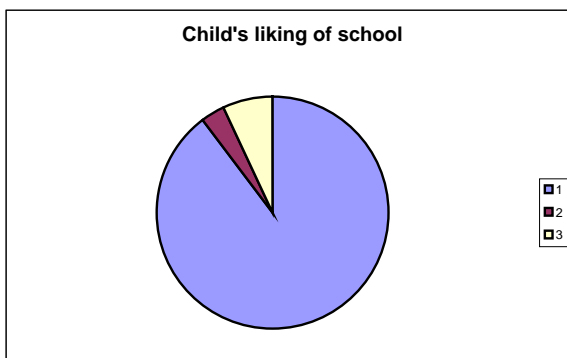
**Figure 6.13** Importance of education

All the respondents agreed that the education of the child with cerebral palsy is important, at least to a certain degree. The majority of respondents (91%) gave a positive response without any reservations.

Question 15: Does your child like the school? Yes / No / Do not know

**Table 6.14** Child's reaction to school

Child's liking of the school	Number and percentage of respondents
1. Yes	140 (90%)
2. No	5 (3%)
3. Do not know	11 (7%)
<b>Total</b>	<b>156</b>



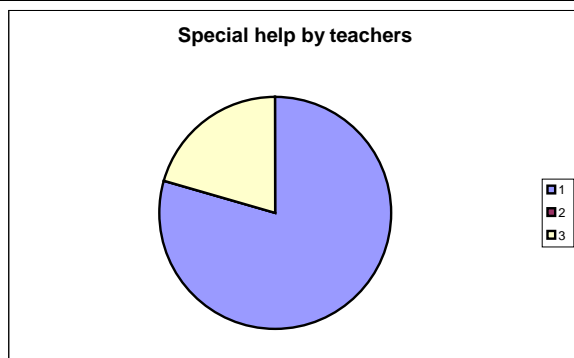
**Figure 6.14** Child's reaction to school

Most of the learners like the school according to the respondents.

Question 16: Do the teachers give your child special help? Yes / No / Do not know

**Table 6.15** Help given by teachers

Special help by teachers	Number and percentage of respondents
1. Yes	124 (79%)
2. No	0
3. Do not know	32 (21%)
<b>Total</b>	<b>156</b>



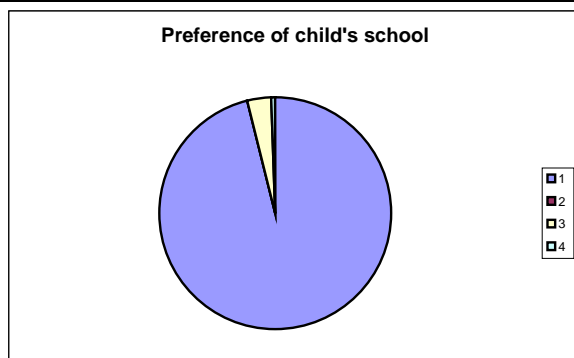
**Figure 6.15** Help given by teachers

Although the majority of respondents indicated that their children receive special help from their teachers, one-fifth was unaware of the state of affairs at school.

Question 17: Which school do you prefer your child to attend? Special / Inclusive (teachers also pay special attention) / Ordinary

**Table 6.16** School preference

School preference for CP child	Number and percentage of respondents
1. Special	150 (96%)
2. Inclusive	0
3. Ordinary	5 (3%)
4. Question not answered	1 (1%)
<b>Total</b>	<b>156</b>



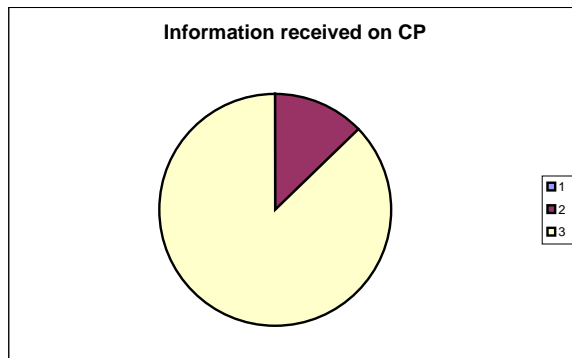
**Figure 6.16** School preference

Most respondents prefer the learners to attend a special school. The option of inclusive education was not considered.

Question 18: How much information did you receive on cerebral palsy? A lot / Little / Nothing

**Table 6.17** Information received on cerebral palsy

Information received on CP	Number and percentage of respondents
1. A lot	0
2. Little	20 (13%)
3. Nothing	136 (87%)
<b>Total</b>	<b>156</b>



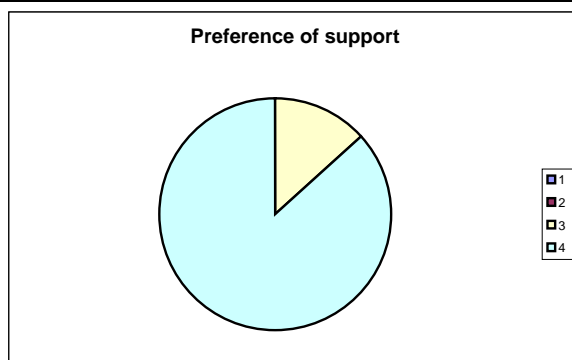
**Figure 6.17** Information received on cerebral palsy

The majority of respondents had never received any information about cerebral palsy.

Question 19: In which one of these activities would you like to take part? Individual counselling / Group counselling / Discussion with other parents / Parent-teacher discussion group

**Table 6.18** Preferred support

Preference of support	Number and percentage of respondents
1. Individual counselling	0
2. Group counselling	0
3. Discussion with other parents	21 (13%)
4. Parent-teacher discussion group	135 (87%)
<b>Total</b>	<b>156</b>



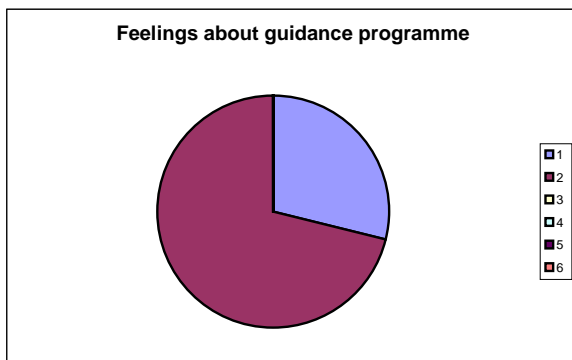
**Figure 6.18** Preferred support

Most of the respondents would prefer to be part of a parent-teacher discussion group. This might indicate that they either have great confidence in teachers or would like to be more involved in their children's education.

Question 20: How do you feel about a guidance programme for parents with children with cerebral palsy? Very positive / Positive / Neutral / Negative / Very negative / Unsure

**Table 6.19** Response to parent guidance programme

Feelings about a guidance programme	Number and percentage of respondents
1. Very positive	45 (29%)
2. Positive	111 (71%)
3. Neutral	0
4. Negative	0
5. Very negative	0
6. Unsure	0
<b>Total</b>	<b>156</b>



**Figure 6.19** Response to parent guidance programme

All the respondents felt either very positive or positive about a parent guidance programme.

## 6.4 Conclusion

The interpreted data of the questionnaire distributed to Xhosa parents who have children with cerebral palsy, brought the following to the fore:

- The questionnaire was mainly completed by mothers of whom approximately half are married. Nearly one-third of the marriages or relationships with partners have been affected as result of the child's cerebral palsy, despite tribal customs that require couples to deal with many difficulties in their relationship.
- Most of the respondents have a primary school education, an important aspect which should be taken into account for the design of guidelines for the parent guidance programme.
- More than half of the respondents are unemployed which is probably linked to the general low level of education.
- Nearly two-thirds of the respondents only have one or two children which is quite uncommon in Xhosa families. It seems as if the birth of a child with cerebral palsy discourages parents to have more children.



- Most of the children were affected by cerebral palsy at an early age. Respondents are very ill-informed about cerebral palsy, yet they have had to raise a child who was affected by the condition in infancy or very early in childhood.
- The ratio of cerebral palsy indicates that about twice as many boys are affected than girls. Since boys are more valued in the Xhosa culture, this can be a significant blow to the family.
- Respondents generally felt hurt after the child had been diagnosed with cerebral palsy.
- Respondents predominantly feel that it is difficult to care for a child with cerebral palsy. However, the respondents generally receive strong to adequate support from their family members.
- Nearly half of the children with cerebral palsy are fairly isolated from the outside world as they do not accompany their parents on outings. Their life world is limited to the home and school.
- All respondents agreed that the education (at least to a certain degree) of their children with cerebral palsy is important.
- Most respondents indicated that their children are happy at the special school that they attend. They receive special help from the teachers to a large extent. This explains the preference of the respondents for the special school. The option of inclusive education was not even considered by the respondents.
- The respondents' greatest need is to be involved in a parent-teacher discussion group. This might indicate that they either have great confidence in teachers and view them as figures of authority pertaining to cerebral palsy, or that they would like to be more involved in their children's formal education.
- All the respondents feel positive about a guidance programme for parents with children with cerebral palsy.

Chapter 7 will highlight the guidelines for the guidance programme.

## **CHAPTER 7: GUIDELINES FOR A PARENT GUIDANCE PROGRAMME**

### **7.1 Introduction**

One of the research questions (1.7.2) was to establish whether Xhosa parents of learners with cerebral palsy need a parent guidance programme. The findings of the empirical study presented in the preceding chapter indicate that Xhosa parents with children with cerebral palsy are generally ill-informed about the condition; their greatest need is to be involved in a parent-teacher discussion group; and they feel positive about a parent guidance programme for parents with children with cerebral palsy.

The researcher will proceed in this chapter with the second research question, namely what guidelines can be given pertaining to such programmes. It would seem from the parents' perspective that teachers are the most suitable group to present these guidance programmes. While not overlooking the heavy workload of teachers, teachers have the responsibility of a community and pastoral role according to Government Notice 82 of 2000, in which the Department of Education describes the norms and standards for educators in the National Education Policy Act, 1996. Pertaining to the community and pastoral role, it is stated that the educator will practise and promote a critical, committed and ethical attitude towards developing a sense of respect and responsibility towards others. The educator will develop supportive relations with parents based on a critical understanding of community issues. In the researcher's opinion, a critical dimension implied in this role is cerebral palsy education for parents with children with cerebral palsy.

The context of the proposed guidelines for the guidance programme is against the backdrop of special education, broadly the equivalent of full-service schools (3.4.2.3), although the latter has a much more encompassing role within the context of inclusive education. In the survey parents and caregivers did not consider the option of inclusive education (question 17, section 6.3). This can probably be ascribed to their lack of familiarity with the concept, and the belief that their children's needs are best taken care of in the current special school setting. Parents may also be suspicious of the motives of those who argue that special schools are not necessarily the best option (4.8.2.2). However, the presentation of a guidance programme for Xhosa parents with children with cerebral palsy already reflects one of the roles of a full-service school.

## **7.2 Guidelines for practical issues**

The following issues should be taken into account when developing a parent guidance programme:

- Some parents live very far from the school (1.12); therefore the guidance programme should be presented in a condensed format on days when most parents are at the school. Since the days on which the school closes for the holidays is inconvenient for teachers who are looking forward to a well-deserved break, the only remaining option is the beginning of the new term(s). Parents usually accompany their children when they bring them back to school.
- Parents can be invited to attend the guidance programme by means of a mailed letter.
- It would be ideal to offer the guidance programme in the afternoon to avoid disrupting the education of the learners. However, as some parents need to embark on their long journey home by then, it should be presented during the course of the morning. The benefit of empowering the parents and providing them with additional information should be weighed against the disruption for the learners who would have to join another class should their teacher be one of the presenters.
- The programme should be presented in Xhosa or an interpreter should be present.

## **7.3 General guidelines for the guidance programme**

- The level of the parents' education should be taken into account. According to the survey, most parents only have a primary school education (6.4). Printed material, if any, should be richly illustrated to communicate the message, intricate medical terms should be avoided as most people battle with understanding jargon and concrete teaching aids should be available throughout the presentation. If commercial models and posters are not available, they can be made from clay or paper mache. Create colourful and original illustrations with paint and/or scraps. Glue waste material (scraps of material, lace, wool, beads, buttons, plant material, plastic, pebbles, shells, feathers, etc.) to a drawing of the brain to show the division of the four lobes.
- Specific information that is not relevant to all parents can be included in separate leaflets. Sponsors should be approached to help carry the cost.

An example of a leaflet that a parent with a wheelchair bound child can take home to share with other caregivers could contain the following information:

## GENERAL TIPS ON WHEEL CHAIRS

1. Wheelchair tyres that get punctures as a result of the rough surfaces on which they are used, cause a lot of inconvenience. It is possible for learners who live in the country to get perma tubes, which will not develop holes and loose air. These tyres are slightly heavier than tyres filled with air, but can save a lot of trouble.
2. When you go on an outing, the chair can easily be folded up and taken along. Just check that the footrest is up before you fold up the chair.
3. If the learner is capable of pushing himself or herself (in other words, propelling the wheelchair), he or she must be encouraged to do so. Help should only be provided when necessary.
4. A wheelchair should be treated with the greatest respect. It is the 'legs' of one who cannot walk.
5. The chair should always be kept in a good condition. It should be regularly washed and oiled so that it can be used at its best for a long time.
6. A chair is made for one person's specific needs and other children must never climb up behind the chair to ride along, for instance, when going down a slope. They must also never sit in the chair on the learner's lap.
7. A wheelchair is a learner's aid and should under no circumstances be used to transport books, wood, water or anything else.
8. Take care that the brakes are on when the person climbs in and out of the chair. This will prevent the chair sliding away and the person falling.
9. Never let the chair stand on a slope unless the brakes are on.
10. Before the person stands up, the footrest must be lifted and the feet placed on the ground to shift the weight, otherwise the chair will tip up from behind and he or she will fall forward.
11. Behind the chair are two tipping levers with rubber covered ends. When pushing the chair and you come to stairs or something laying in the way, for example, a hosepipe, or to a surface such as grass or gravel, you must tread on this lever. The front wheels of the chair will lift up so that the chair tilts backward and you can easily get over the obstacle.
12. It is a good idea for a person who is severely disabled or impaired to be fastened into the chair, preferably with a safety belt like that used in a car. The buckles are stronger and more reliable than Velcro. You can obtain them relatively cheaply from a scrap yard.
13. When going up a slope, the person in the wheelchair should lean forward; thus displacing the weight again. This will prevent the chair from tilting or even toppling over backward.
14. To go up stairs the chair must be turned around, so that the big back wheels go up first. It is safer if two people help to lift up the front of the chair, especially if the wheelchair user is large and heavy.
15. When descending stairs, the chair's front wheels must be lifted up to go down the stairs with the back wheels, again with extra help if available.
16. If the learner must be moved from the wheelchair to another chair, a bed or a vehicle, it should be done as follows:
  - If the learner can do it alone, perhaps using a plank that has been specially made for the purpose, then he or she should do so.
  - If not, the chair must be pushed as close as possible to the other chair or the car. Make sure that the brakes are on and lift up the footrest. Someone must stand behind the chair and put his or her arms under the arms of the learner in the wheelchair,

grasping his or her own wrists. The learner in the chair can hold onto the person who is behind him or her. Another person must pick up the learner's legs by the knees. The person should be lifted high enough that he or she is not dragged and placed onto the other seat or bed. If the person has to sit on a cushion, someone must first move the cushion from the wheelchair to the chair that the person is moving to. This is not usually necessary in a car.

(Kilian in Krüger & Groenewald 2004a and 2004b)

- All interested parties should be invited to attend the guidance programme presentations. The respondents generally receive strong to adequate support from their family members (6.4) and these people should also be empowered by the guidance programme to enhance the value of their support. The learner with barriers is cared for within the extended family since education is not only the responsibility of the nuclear family. The extended family involves grandfathers, grandmothers, uncles, aunts, brothers, sisters, cousins, nephews and nieces (4.7.2).
- The majority of parents or caregivers never received information about the cerebral palsy of their child (question 18, section 6.3). Thus, the scope of the guidance programme should be extended beyond learners of school going age. Word should be sent to the community so that all parents or caregivers with children with cerebral palsy are invited to attend.
- Getting word to the community can be done through the media – newspapers and the radio. The expectation is that the message will be communicated further by word of mouth. The set dates for the guidance programmes, namely the days on which the school reopens for the new terms, should also be included. Fliers in the administrative offices can also convey the message.
- Small beginnings should not be regarded as failures as the message will probably take time to spread.
- A dedicated and informed teacher team should head the presentations. They should always be ready to present the programme on days when the school reopens. This includes a designated venue which has to be prepared in advance.
- The high level of unemployment (question 5, section 6.3) will most likely contribute to poverty. Consequently, private specialised medical and paramedical services may be beyond the reach of most parents. Innovative alternatives should be suggested such as the play of word games to improve language and speech.

#### **7.4 Guidelines pertaining to traditional healers**

The methods used by traditional healers in diagnosing and treating cerebral palsy are described in 2.9.1. "Traditional healers are readily accepted and understood by black

communities as they have the same or similar cultural and African religious background” (Semela 2001:133). It is also “apparent that traditional and faith healers have had significant success in providing support systems for families with brain damaged children” (Semela *ibid*).

- The guidance programme should not oppose or challenge traditional medicine. It provides an alternative way to deal with cerebral palsy.
- The guidance programme can also be regarded as supplementary to traditional medicine within the context of the Xhosa culture.

## **7.5 Guidelines for the structure of the parent-teacher discussion group**

The characteristics of a meeting as provided by The Department of Education: First Steps School Governance Starter Pack (1997:27) can also be applied to parent-teacher discussion groups. Some of them are listed below.

- *The parent-teacher discussion group has a purpose*, namely to assist the parents or caregivers with taking care of their children with cerebral palsy. In order to achieve the goal, the guidance programme should be clearly structured beforehand and evaluated afterwards to determine whether it has met its goal. Adjustments can follow upon reflection.
- *The members contribute to the discussion*. Their contributions should be valued. Some parents need directive support but should never be talked down to. The approach should not allow for authoritarians who operate from a position of power. The teacher should rather take the stance that he or she can also learn from the parents or caregivers.
- *The members share their ideas briefly*. Care should be taken that one or two parents do not dominate the discussion.
- *The discussion group adheres to the allocated time*. The researcher is of the opinion that the duration of the guidance programme should not exceed two hours. Naturally a complete guidance programme cannot cover all the required topics associated with the multifaceted phenomenon of cerebral palsy in such a short period of time. Thus, the researcher envisages that the guidance programme should consist of at least two modules that will ultimately run concurrently. The guidance programme should commence with an introductory two-hour module which will cover basic topics cursorily. Time will show whether there is a demand for a more advanced module.

- *The chairperson/leader focuses the discussion group.* Care should be taken that individuals do not sidetrack the programme. Such individuals can be invited to join an individual discussion afterwards.
- *The atmosphere is friendly.* The group members should experience compassion. Their cultural background such as the difficulties of dealing with a male with an impairment (6.4) should be handled with sensitivity. As stated in 4.7.2, a Xhosa learner with a barrier to learning may be regarded as a threat to the biological continuation in a family; not being able to contribute economically to family and social prosperity; and a danger to the spiritual existence of the community. Africans believe that learners with barriers to learning are responsible for bringing the wrath of God and of the ancestors upon them. Therefore, disasters such as drought, illness and death are attributed to these learners.

#### **7.6 Guidelines for the introductory two-hour module – “Getting to know yourself and your child with cerebral palsy”**

- Explain (define) the condition cerebral palsy (1.6.3)
- Display a model of the brain (obtain one from the Life Science class or make one) and conduct a very basic discussion on the main functions of the four lobes (2.4.1). Highlight the frontal lobe, which is associated with movement, the parietal which is responsible for all sense of touch, the occipital which analyses and interprets visual stimuli, and the temporal which controls auditory abilities and associated language activities.
- Mention that other structures of the brain are also involved in movement, balance and posture. These structures need not necessarily be named but the basal ganglia (2.4.1.2) and the cerebellum (2.4.1.3) should be referred to.
- Direct the discussion to injury in any of these areas that will affect functioning.
- Talk about increased muscle tone (the muscles are stiff and awkward because the muscles are too tight), reduced muscle tone (the muscles are too relaxed) and a combination of these two tones (2.5).
- Discuss some of the types of cerebral palsy, including spasticity with regional and global involvement (2.5.1.1), athetotic cerebral palsy and various involuntary movements such as ataxia (2.5.1.2), as well as mixed types (2.5.1.3).

Below is an example of how such a discussion can be conducted:

There are different kinds of cerebral palsy and you will recognise the forms when we discuss them. The first common kind is spasticity. Many people are either born with brain damage which is

associated with spasticity, or it can emerge after a car accident. One obvious characteristic of spasticity is increased muscle tone (the muscles are taut), which is particularly obvious at the elbow – the so-called chicken-wing arm. The thumb is also often folded into the palm of the hand and the wrist bends toward the body. The heel muscles may also be shortened and the person consequently walks on his or her toes. The knee could also be bent. Spasticity is a very common form of cerebral palsy and it often occurs on one side of the body only. This is known as hemiplegia. If the left side is affected, it is known as left hemiplegia and if the person's right side is affected, we refer to him or her as a right hemiplegic. The degree of spasticity can also range from mild to severe.

We often make the mistake of thinking that people who are spastic are also less intelligent. It all depends on the extent of the brain damage. It is important to remember that someone's appearance does not reflect their intelligence. A person who dresses in the latest fashions and is very well groomed is not necessarily intelligent. Similarly, someone who looks different physically, is not necessarily unintelligent.

When some people have had too much alcohol, they no longer walk normally. They lift their feet too high. Others have difficulty talking properly, for example, they slur their words and cannot pronounce things correctly. Sometimes they slam things down, because they have trouble judging distance: the table top, for instance, is closer than it seems, so they put down the glass too heavily. These symptoms are temporary and disappear when that person sobers up. In the same way that alcohol impairs the way our brain functions temporarily, so cerebral palsy can permanently impair people's brain functions. (The brain is also known as the *cerebrum*, which is where we get the term *cerebral*.)

A person who drinks too much alcohol can show temporary symptoms that correspond to ataxia, a form of cerebral palsy. Just as alcohol affects brain functions temporarily, so people who are ataxic have problems with certain brain functions. They have most difficulty with balance, poor co-ordination and clumsiness. They also have difficulty gauging the dimension of their movements and experience problems with tasks of a rhythmic nature. Imbalance of the eye muscles can make reading difficult and speech is often slurred. Sometimes they tremble, especially when they are concentrating hard on a task. When they write this trembling will be reflected in their writing.

(Krüger & Groenewald 2004b)

- Limit discussions on the causes of cerebral palsy to developmental malformations and brain injury, sustained before, during or after birth (2.6.2).
- Briefly mention associated conditions of cerebral palsy such as intellectual impairment (2.7.1), epileptic seizures (2.7.2), visual problems (2.7.3), hearing impairments (2.7.4), language and speech problems (2.7.5), sensory problems (2.7.6), learning problems (2.7.7), feeding and nutritional problems (2.7.8), and Attention Deficit Hyperactivity Disorder (2.7.9).



- Touch on the effects of a learner with barriers to learning on parents, in particular parental coping strategies (4.4.2.2).
- Highlight the learner's right to be included in society

Below is an example of how such a discussion can be conducted:

It was only recently that full inclusion of the disabled began to come about in the South African context. But let's look at it from a different angle. Have you ever noticed that when people make a mistake they often say: "No-one is perfect. Anyone can make a mistake"? They are quite right! No-one is perfect. Each one of us has a barrier of some kind. We often tend to think that people who have an impairment or disability like cerebral palsy or poor vision are the ones with barriers. The whole idea is to do away with these categories, because no one is perfect.

There is a wide range of impairments, of which we mention only a few. Anyone who wears glasses has a visual impairment that could range from minimal to severe. People who tend to get depressed have an emotional impairment. The same applies to people who cannot control their temper and often get into fights. Their emotions are impaired because they cannot be controlled. This also applies to moody people. Even lazy people are impaired by their inability to apply self-discipline. Do you begin to understand how broad this issue is and that we are actually all affected by it?

You might think that laziness is less permanent than having to cope with an artificial limb. But that's not exactly true – each day we establish patterns of behaviour that become part of our personality over the years and it takes substantial effort to correct them. There is plentiful evidence of people with artificial limbs who are not 'impaired' in any way. Do you see why, if you refer to so-called disabled people, you could also include yourself in that category? You do not want to be excluded from society. Neither does the child with cerebral palsy.

(Krüger & Groenewald 2004a and 2004b)

- Conclude the discussion by providing practical tips, for example:
  - Making a communication board to facilitate communication. Communication boards have pictures, symbols, letters, or words attached. The child communicates by pointing to or gazing at the pictures or symbols.
  - Parents can also adapt eating utensils by slightly bending the tip of the spoon and pad the handle for better grip.
  - Cluttered areas increase the potential for falls. Also, children with cerebral palsy are more likely to fall because of inadequate balance especially on surfaces coated with manure.
  - Rubbing a spastic limb can reduce the tension.

## **7.7 The advanced module**

An advanced module can be developed on parents' demand to include topics of their choice. Although difficult to predict their needs, mobility issues or the future of their child might be high on their priority list.

## **7.8 Conclusion of the study**

The next chapter will deal with a summary of the research, limitations of the study and recommendations for further study.

## **CHAPTER 8: SUMMARY, LIMITATIONS AND RECOMMENDATIONS FOR FURTHER RESEARCH**

### **8.1 Introduction**

This chapter functions as a summary of the research project. Recommendations are made for further research and the shortcomings of this particular study are presented.

### **8.2 Purpose of the research**

The main aim of the research is to determine whether Xhosa parents with children with cerebral palsy require parent guidance programmes to assist them coping with their learners and to provide specific guidelines for the design of such programmes where needed. In order to achieve the goal, a systematic research plan was developed in Chapter 1.

### **8.3 Executed research plan**

The research commenced with the formulation of a problem which was formulated in this study as follows (1.7.2):

Do Xhosa parents of learners with cerebral palsy need parent guidance programmes? If such programmes are needed, what guidelines can be given pertaining to such programmes?

In order to find answers to the research problems, an extensive literature study was conducted on the phenomenon of cerebral palsy and support services (Chapter 2), inclusive education in South Africa with special reference to learners with barriers to learning such as those with cerebral palsy (Chapter 3), and attitudes of Xhosa parents towards their learners with cerebral palsy (Chapter 4). After the exposition of the research design and methodology in Chapter 5, an empirical study was undertaken and described in Chapter 5. The findings of the study were reported in Chapter 6. It transpired that Xhosa parents and caregivers are in need of parent guidance programmes. Findings from the literature and the empirical study contributed to the formulation of guidelines for a guidance programme for Xhosa parents with children with cerebral palsy (Chapter 7).

## **8.4 Summary of literature and empirical investigation**

### **8.4.1 Literature summary**

The term cerebral palsy refers to any one of a number of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination but do not worsen over time. Even though cerebral palsy affects muscle movement, it is not caused by problems in the muscles or nerves. It is caused by abnormalities in parts of the brain that control muscle movements. The majority of children with cerebral palsy are born with it, although it may not be detected until months or years later. The early signs of cerebral palsy usually appear before a child reaches three years of age. The most common are a lack of muscle coordination when performing voluntary movements (ataxia); stiff or tight muscles and exaggerated reflexes (spasticity); walking with one foot or leg dragging; walking on the toes, a crouched or a 'scissored' gait; and muscle tone that is either too stiff or too floppy. Because cerebral palsy involves the brain and the brain controls so many of the body's functions, cerebral palsy can also cause epileptic seizures, impair intellectual development, and affect vision, hearing, and behaviour. Some children with cerebral palsy have difficulty feeling simple sensations, such as touch. Treatment of cerebral palsy can involve traditional healing or Western medicine.

Learners with more disabling types of cerebral palsy are educated in special schools. The medical view labels learners in terms of disability and gave rise to the concept of specialized education. This concept is not acceptable as it accentuates exclusion and marginalisation of learners, which eventually often results in stigmatization of learners. The South African government is determined to create special needs education as a non-racial and integrated component of the education system. Special schools will gradually be replaced by full-service schools as inclusive education is defined as a learning environment that promotes the full personal, academic and professional development of all learners irrespective of race, class, gender, disability, religion, culture, sexual preference, learning styles and language. The inclusion of learners with learning barriers into mainstream classes is part of a universal human rights movement. One of the envisaged consequences of inclusive education is that peers of learners with barriers to learning experience the diversity of society. They encounter this in other learners' appearances that are different physically, intellectually and emotionally.

The well-being of an individual with cerebral palsy depends upon the strength and well-being of his or her family. For parents to accept a child's disabilities and come to grips with the extent of

their caregiving responsibilities will take time. In impoverished rural African contexts, parents also have to overcome the widespread prejudices and suggestions propagated by witchcraft, which is practised in many areas. Parents and caregivers may use different coping skills to adjust themselves to the child with cerebral palsy. Coping strategies such as denial, avoidance and aggression may be negative, but they are a step towards a positive adaptation to the stress of having a child with a disability. Other results of stress in parents can include burn-out, aloneness and parents' exclusion by friends and community, feelings of inadequacy, anxiety, grief and depression.

#### **8.4.2 Summary of empirical investigation**

A survey of a sample of Xhosa parents gave rise to the following findings. Most respondents have a primary school education, an important aspect which should be taken into account during the design of guidelines for the parent guidance programme. Most of the children were affected by cerebral palsy at an early age. Respondents are very ill-informed about cerebral palsy, yet they have had to raise a child who was affected by the condition in infancy or very early in childhood. Respondents predominantly feel that it is difficult to care for a child with cerebral palsy. Their greatest need is to be involved in a parent-teacher discussion group. All the respondents feel positive about a guidance programme for parents with children with cerebral palsy.

#### **8.5 Limitations of the study**

The empirical study was limited to quantitative research consisting of a single data gathering instrument, a questionnaire with 20 closed questions. Qualitative research by means of structured interviewing would have enriched the data.

#### **8.6 Recommendations for further study**

A guidance programme for Xhosa parents with children with cerebral palsy should be developed according to the proposed guidelines and empirically tested.

The need for a guidance programme for Xhosa children with cerebral palsy should be established.

## **8.7 Conclusion**

Children with cerebral palsy are entitled to develop to their fullest potential and empowering their parents or primary caregivers can contribute to realizing this basic human right. The guidelines for the guidance programme for Xhosa parents is a step that direction.

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## APPENDIX A: COVER LETTER TO PARENT

Glen Avent Convent  
P.O. Box 261  
Umtata  
5100  
Phone: 047-5350701/2  
Fax: 047-5350707  
E-mail: [ecsecr@intekom.co.za](mailto:ecsecr@intekom.co.za)

Dear Parent

Will you please assist me by completing the enclosed questionnaire? I am conducting research into the needs of Xhosa parents of children with cerebral palsy. The aim of the research is to help you and other parents of children with such barriers. Please return the questionnaire not later than ... (date to be inserted). Use the included stamped and addressed envelope to post the questionnaire back to me. Alternatively, you can bring the questionnaire to the school when you fetch your child. Please hand it in at the principal's office.

If there is anything you do not understand or if you need another questionnaire, please contact me using the above address, phone number, fax or e-mail.

Please try and answer the questions as truthfully as possible. There are no right or wrong answers. Your name and address will remain confidential. Kindly note that I am relying entirely on your co-operation and that you are under no obligation to complete the questionnaire. Thank you for your time! Your assistance is appreciated.

Yours faithfully

Miss T. Sello

## APPENDIX B: QUESTIONNAIRE: XHOSA PARENTS WITH CHILDREN WITH CEREBRAL PALSY

Please mark the answer in the box with an X, e.g.

X
---

1. Are you a Xhosa parent?

Yes 

--

No 

--

2. What is your relationship with the learner with barriers?

- Mother
- Father
- Guardian


3. What is your marital status?

- Married
- Divorced
- Widowed
- Single parent


4. Which standard did you pass?

- No schooling
- Sub A
- Sub B
- Primary school
- High school
- Matric
- Post Matric qualifications


5. What is your employment status?

- Unemployed
- Retired
- Employed
- Self-employed


6. How many children do you have in the family?

- One to two
- Three to four
- Five to six
- Seven to eight
- Nine to ten
- More than ten


7. To the best of your knowledge approximately when did cerebral palsy affect your child?

- Born having it - 1 year
- 2-3 years
- 4-5 years
- 6 years and older


8. What is the sex of your child?

- Male
- Female


9. Shortly after your child was diagnosed with cerebral palsy, what was your primary feeling?

- Hurt
- Chronic sorrow
- Acceptance


10. Do you agree with the following statement?  
It is difficult to care for your child with cerebral palsy

- Yes
- No


11. Is or was your marriage or relationship with your companion affected by the child's cerebral palsy?

- Yes
- No
- No longer affected


12. How much support did you get from family members to educate the child with cerebral palsy at home?

- Much support
- Average support
- No support


13. Do your child with cerebral palsy accompany you on outings?

- Most of the time
- Sometimes
- Seldom or never


14. Do you think it is important to educate your child?

- Yes
- To a certain extent
- No


15. Does your child like the school?

- Yes
- No
- Do not know


16. Do the teachers give your child special help?

- Yes
- No
- Do not know


17. Which school do you prefer your child to attend?

- Special
- Inclusive (teachers also pay special attention)
- Ordinary


18. How much information did you receive on cerebral palsy?

- A lot
- Little
- Nothing


19. In which one of these would you like to take part?

- Individual counselling
- Group counselling
- Discussion with other parents
- Parent-teacher discussion group


20. How do you feel about a guidance programme for parents with children with cerebral palsy?

- Very positive
- Positive
- Neutral
- Negative
- Very negative
- Unsure


Thank you for your time! Your assistance is appreciated.